



Strengthening **PMTCT**
through communication:
A review of the literature

August 2009



Strengthening PMTCT through communication

A review of the literature

Abstract

A literature review on social mobilization and communication in support of prevention of mother to child transmission (PMTCT) of HIV. Prepared as part of a research project in support of the South African 'Operational Plan for Accelerating PMTCT Services' with the support of UNICEF. The preparation of this literature review was supported by funding and technical assistance from UNICEF, South Africa.

August 2009

Centre for AIDS Development, Research and Evaluation (CADRE)



Supported by UNICEF South Africa



unite for children

Authors

Kerry Frizelle
School of Psychology
University of KwaZulu-Natal
Howard College Campus

Vernon Solomon
School of Psychology
University of KwaZulu-Natal
Pietermaritzburg Campus

Dr Asta Rau
Centre for AIDS Development, Research and Evaluation (CADRE)
Rhodes University
Grahamstown

Acknowledgements

Dr Jude Clark
School of Psychology
University of KwaZulu-Natal
Howard College Campus

Tarryn Frankish
School of Psychology
University of KwaZulu-Natal
Howard College Campus

Project management and technical assistance**CADRE**

Dr Kevin Kelly
Helen Hajjiannis

UNICEF South Africa

Dr Joan Matji
Dr Ngashi Ngongo

Recommended citation

Frizelle, K. Solomon, V. & Rau, A. (2009). Strengthening PMTCT through communication and social mobilisation: A review of the literature. Johannesburg: CADRE.

Disclaimer

Preparation of this report was supported by UNICEF, but does it not necessarily represent the views of UNICEF.

Contents

| | |
|--|----|
| 1. Executive Summary | 1 |
| 2. Methodology of the review | 3 |
| 3. Introduction and background to PMTCT in South Africa | 4 |
| 3.1 HIV/AIDS and MTCT in southern-Africa and South Africa | 4 |
| 3.2 PMTCT in South Africa: Operational and political history | 5 |
| 4. Relevant HIV/AIDS policies in South Africa | 7 |
| 4.1 The HIV and AIDS and STI Strategic Plan for South Africa (2007-2011) | 7 |
| 4.2 Policy and guidelines for the implementation of PMTCT | 7 |
| 4.3 Department of Health Strategic Plan 2009/10 - 2011/12 | 8 |
| 4.4 SANAC Programme Implementation Committee meeting | 8 |
| 5. Communication in the context of HIV/AIDS | 10 |
| 5.1 Communication theories and approaches in the context of HIV/AIDS | 10 |
| 5.2 Communication for social change: An integrated approach | 11 |
| 5.3 JHU's Social Ecology Model | 11 |
| 6. Communication theories and approaches in use in PMTCT programmes | 12 |
| 6.1 Communication for development and the ACADA process | 12 |
| 6.2 Communication for development in the South African context | 12 |
| 6.3 Behaviour change communication (BCC) | 12 |
| 6.4 Information education communication (IEC) | 12 |
| 6.5 Community-oriented approach to behaviour change | 12 |
| 6.6 Targeted education messages and communication | 13 |
| 6.7 Interpersonal communication (IPC) | 13 |
| 6.8 Communication for social change | 13 |
| 7. Barriers to PMTCT | 14 |
| 7.1 Societal barriers | 14 |
| 7.1.1 Health care infrastructure and shortage of staff | 14 |
| 7.1.2 Healthcare workers' poor attitudes and interactions with clients | 15 |
| 7.1.3 Poor quality of counselling and information | 16 |
| 7.1.4 Inadequate family-planning services and counselling | 17 |
| 7.1.5 Inadequate integration of services | 18 |
| 7.1.6 Poor referral links | 18 |
| 7.1.7 Lack of communication within the healthcare system | 18 |
| 7.1.8 Poverty and infrastructure | 19 |
| 7.1.9 Overlooking the needs of youth | 19 |
| 7.1.10 Cultural factors | 20 |
| 7.2 Community barriers | 21 |
| 7.3 Social network barriers | 21 |
| 7.3.1 Stigma | 21 |
| 7.3.2 Gender related issues and male partner/husband support | 21 |
| 7.4 Individual barriers | 22 |
| 7.4.1 Lack of awareness and knowledge | 22 |
| 7.4.2 Confusion and dilemmas around infant-feeding options | 23 |
| 7.4.3 PMTCT practices that are perceived of as discriminatory | 24 |
| 7.4.4 Psychological barriers | 24 |
| 8. Key participants to be reached through communication strategies | 25 |
| 8.1 Societal participants | 25 |
| 8.1.1 Health care workers in rural and urban sites | 25 |
| 8.1.2 Representatives from various clinics, hospital sites and services | 25 |
| 8.1.3 Relevant government departments and policy makers | 25 |
| 8.2 Community participants | 26 |
| 8.2.1 Community outreach workers | 26 |
| 8.2.2 Community organizations | 26 |

| | |
|---|-----------|
| 8.3 Social networks | 26 |
| 8.3.1 Influential community members | 26 |
| 8.3.2 HIV-positive women's families | 27 |
| 8.4 Individual participants | 27 |
| 8.4.1 HIV-positive men and women (rural and urban) | 27 |
| 8.4.2 HIV-negative women and men (rural and urban) | 27 |
| 9. Key themes to be communicated in PMTCT messages | 29 |
| 9.1 Societal level | 29 |
| 9.1.1 Caring, non-judgmental and non-discriminatory attitudes and actions | 29 |
| 9.1.2 Sexual and reproductive rights of HIV-positive women | 29 |
| 9.1.3 The importance of family planning | 29 |
| 9.1.4 Approaches to HIV-testing for pregnant mothers | 30 |
| 9.1.5 The importance of a family-centred model for health | 30 |
| 9.1.6 The importance of on-going support for mothers | 30 |
| 9.1.7 On-going training of healthcare workers to ensure quality services | 30 |
| 9.1.8 Integrated ANC, PMTCT, postnatal care and family-planning services | 30 |
| 9.1.9 Information on infant-feeding options and the need for counselling | 30 |
| 9.1.10 Up-to-date information about programme implementation | 31 |
| 9.1.11 Relevant policies and changes in policies | 31 |
| 9.1.12 Socio-economic and infrastructure constraints on PMTCT uptake | 31 |
| 9.1.13 The importance of partnering with relevant NGOs | 32 |
| 9.2 Community level | 32 |
| 9.2.1 Beliefs about reproduction, childbearing and childrearing | 32 |
| 9.3 Social networks level | 32 |
| 9.3.1 Importance of male support and engagement | 32 |
| 9.3.2 Disclosure skills | 33 |
| 9.3.3 Gender equity and women's rights | 33 |
| 9.4 Individual level | 33 |
| 9.4.1 Key components for HIV prevention at an individual level | 33 |
| 9.4.2 Accurate facts about HIV/AIDS, MTCT and the PMTCT | 33 |
| 9.4.3 Importance of knowing your HIV status | 34 |
| 10. Good practices | 35 |
| 11. Strategies for strengthening PMTCT | 37 |
| 11.1 Societal level | 37 |
| 11.1.1 Media communication strategies | 37 |
| 11.1.2 Recommendations | 38 |
| 11.2 Community level | 39 |
| 11.2.1 Media communication strategies | 39 |
| 11.2.2 Recommendations | 40 |
| 11.3 Social network level | 42 |
| 11.3.1 Communication strategies | 42 |
| 11.3.2 Recommendations | 42 |
| 11.4 Individual level | 42 |
| 11.4.1 Communication strategies | 42 |
| 11.4.2 Recommendations | 43 |
| 12. Implications and recommended areas for future research | 45 |
| 12.1 Recommendations for future research | 45 |
| 12.1.1 Gender ² | 45 |
| 12.1.2 Individual experience and perception | 45 |
| 12.1.3 Knowledge | 45 |
| 12.1.4 Reproduction rights, desires, beliefs | 46 |
| 12.1.5 Infant feeding | 46 |
| 12.1.6 Health systems | 46 |
| 12.1.7 Counselling and testing | 46 |
| 12.1.8 Communication | 46 |
| 13. Conclusion | 47 |
| 14. References | 49 |

Acronyms

| | |
|---------|---|
| ACADA | Assessment, Communication, Analysis, Design, Action |
| AFASS | Acceptability, Feasibility, Affordability, Safety, Sustainability |
| AIDS | Acquired Immune Deficiency Syndrome |
| ANC | Antenatal Care |
| ARVs | Antiretrovirals |
| AZT | Zidovudine |
| BCC | Behaviour change communication |
| CAPRISA | Center for AIDS Programme of Research in South Africa |
| CADRE | Centre for AIDS Development Research and Evaluation |
| CBO | Community Based Organization |
| CHW | Community Health Worker |
| FBO | Faith Based Organization |
| FHI | Family Health Institute |
| HIV | Human Immunodeficiency Virus |
| ICP | Interpersonal communication |
| IEC | Information education communication |
| HSRC | Human Sciences Research Council |
| JHHESA | Johns Hopkins Health and Education in South Africa |
| m2m | Mother to mother |
| m2m2b | Mothers to mothers to be |
| MDG | Millennium Development Goal |
| MRC | Medical Research Council |
| MTCT | Mother to Child Transmission |
| NGO | Non Governmental Organization |
| OBs | Obstetrics |
| PEPFAR | President's Emergency Plan for AIDS Relief |
| PIC | Programme Implementation Committee |
| PLWHA | Person Living with HIV/AIDS |
| PMTCT | Prevent/Prevention (of) Mother to Child Transmission |
| PPTCT | Prevention of Parent to Child Transmission |
| SADC | Southern African Development Community |
| SANAC | South African National AIDS Council |
| STD | Sexually Transmitted Disease |
| TBA | Traditional Birth Attendant |
| TB | Tuberculosis |
| UKZN | University of KwaZulu Natal |
| UNAIDS | United Nations Programme on HIV/AIDS |
| UNICEF | United Nations Children's Fund |
| USAID | United States Agency for International Development |
| VCT | Voluntary Counselling and Testing |
| WHO | World Health Organization |





1. Executive summary

Preventing new HIV infections remains a significant public health challenge for South Africa. The high HIV-infection and mortality rates of under-five-year-olds due to mother-to-child transmission (MTCT) of HIV, together with the continuing need that pregnant HIV-positive women have for antiretroviral drugs (ARVs) and prevention-of-mother-to-child-transmission (PMTCT) interventions, underscore the urgency for renewed efforts to offer quality PMTCT services in South Africa.

This report begins with a historical contextualisation of PMTCT in South Africa by providing a brief overview of the political and operational factors that have shaped policies and interventions concerning HIV and AIDS in general, and factors that have led to delays in implementing the national PMTCT programme more specifically. The present conditions indicate an imperative need for coherent policies and a PMTCT programme with a strong communication strategy.

The first half of the report considers communication strategies in the context of HIV and AIDS and the key barriers to PMTCT. The complex factors that together sustain the HIV/AIDS epidemic in South Africa need to be taken into account in the communication strategy that is eventually adopted. The various limitations of a top-down model of communication draw attention to the need for an approach that is contextually located and involves participatory communication, emphasising dialogue and collective action, and aiming for social as well as individual outcomes.

The report gives an overview of the different communication theories and approaches used in the context of PMTCT in sub-Saharan Africa (e.g., behaviour change communication, information education communication, interpersonal communication, community-oriented behaviour change, targeted education messages, communication for development, and the ACADA process).

The social ecology model describes four levels of address in communication for social and behavioural change: societal, community, social networks, and individual. These levels are used to categorise the findings of the literature according to the following areas: barriers to PMTCT implementation, the key participants to be addressed, key communication themes and messages, and good practices in planning and implementing successful PMTCT communication campaigns.

The numerous factors inhibiting the up-take of PMTCT services, especially in a resource-constrained setting, are listed and described. Barriers to uptake of PMTCT services include:

- Poor healthcare infrastructure, shortages of staff, poor referral links, and a lack of communication between different health services and within the healthcare system. Consequently, PMTCT and family-planning services are poorly integrated.
- Poor-quality counselling and healthcare workers' poor attitudes and interactions with clients.
- Gender-related issues, particularly the role of the male partner in reproductive issues and his involvement in PMTCT services.
- Poverty and structural barriers.
- Cultural factors concerning appropriate behaviours linked to counselling and testing, PMTCT, and stigma, including perceptions of poor social support and discriminatory perceptions of PMTCT practices.
- Lack of awareness and knowledge about HIV/AIDS and MTCT in the general population and among pregnant women or mothers, particularly regarding PMTCT information and services.
- The reproductive and health needs of youths are not adequately addressed.
- Psychological barriers, such as denial, fear of death, or fear of HIV testing and disclosure.

The second half of the report discusses the key participants to be reached through communication strategies as well as the key themes and messages of PMTCT. The following target stakeholders are discussed:

- Healthcare workers in rural and urban sites.
- Relevant government departments and policymakers.
- Community organisations and influential community members.
- HIV-positive and HIV-negative men and women in rural and urban areas, and the families of HIV-positive women.

Emerging from the literature were key themes or messages

concerning PMTCT to be incorporated into PMTCT communication strategies. The importance of consistent and accurate themes and messages is stressed in addition to the need to reach all key participants. Key themes and messages emerging from the available literature on barriers to PMTCT include:

- The importance of non-judgmental and non-discriminatory attitudes and actions towards people living with HIV or AIDS (PLWHA).
- The sexual and reproductive rights of HIV-positive women, and gender equity and women's rights in general.
- Family-planning options for HIV-positive women and their partners and also youths.
- The importance of males' support and engagement in PMTCT.
- The key components of HIV prevention at an individual level, including accurate facts about HIV and AIDS, MTCT and PMTCT.
- Stressing the various HIV-testing approaches available to pregnant women.
- The importance of knowing your HIV status and disclosure skills.
- The importance of a family-centred health model and ongoing support for mothers.
- The importance of on-going training of healthcare workers and counsellors.
- Various cultural, traditional and religious beliefs in relation to reproduction, childbearing and childrearing.
- The importance of integrated ANC, PMTCT and family-planning services.
- Clear, consistent and up-to-date information on infant-feeding practices for the sake of PMTCT.
- Up-to-date information on PMTCT programme implementation and policies.
- Constraints to the uptake of PMTCT services (e.g., socio-economic and infrastructure).
- The importance of partnering with relevant NGOs, FBOs and CBOs.

The concluding section of the report focuses on the need to strengthen PMTCT through interpersonal and community communication strategies, including mass media communication, and addressing stigma reduction and gender equality. In addition, the report describes how the success of PMTCT efforts could be improved by strengthening health systems and integrating services. The review ends with recommendations for future research.



2. Methodology of the review

The literature search for this review included a search for qualitative and quantitative peer-reviewed journal articles, full research reports, summary reports, policy documents, guidelines, and chapters in books. Key words were used to initiate the search for relevant literature, and individual documents in turn were used to identify other relevant literature or organisational websites. A number of academic search hosts, including Ebscohost, Swetswise and Academic Search Complete (through the UKZN's library link) were used to locate academic peer-reviewed articles. Organisational websites (such as those of CAPRISA, HSRC, Panos, the Perinatal HIV/AIDS Research Unit, the Health Systems Trust and the Reproductive Health Research Unit) were also searched to locate relevant literature. Direct contact was made with CAPRISA, which linked the reviewers to the Women's Health and HIV Unit at UKZN Medical School.

Research from a variety of developing countries is included in the review. While South Africa is engaging in relevant and important research, the country's political and operational history around PMTCT appears to have resulted in a lag in research. For example, of the 161 documents that were accessed in preparation for this review, only 59 documents reported directly on PMTCT research or policy within South Africa specifically. Furthermore, 46 of the 59 documents that focused on South Africa commented on PMTCT communication in particular. These documents touched on a variety of communication issues, including: strategies for PMTCT communication, PMTCT counselling, a rights-based approach to counselling, family-centred communication, mass media communication, knowledge levels, the quality of referrals, disclosure to partners, and the communication of PMTCT policy to appropriate stakeholders. A significant body of literature from other developing countries emerged — including India, Zambia, Zimbabwe, Tanzania, Nigeria, Malawi, Botswana and Lesotho. The findings of that research offer valuable insights and possible directions for future PMTCT-related research in a South African context, therefore that literature has been included in the review.

This review covers over 135 documents, made up of journal articles (±75), research reports (±25), documents such as government health policies and guidelines (±34), and chapters from books (2).

3. Introduction and background to PMTCT in South Africa

3.1 HIV/AIDS and MTCT in southern Africa and South Africa

Sub-Saharan Africa, with more than two-thirds of the world's total number of HIV-infected people, remains the region most affected by the HIV/AIDS pandemic.¹ Women continue to be disproportionately affected in this region, representing 61% of people living with HIV. Southern Africa accounts for almost one-third of all new HIV infections and AIDS-related deaths globally, while South Africa is considered to be the country with the largest number of people living with HIV in the world. It is estimated that 5.5 million people in South Africa are living with HIV. In this country, among 15- to 24-year-olds, females account for 90% of all new infections, confirming the gendered nature of the South African epidemic.² Trends in HIV prevalence in South Africa over the last five years show that while there is a gradual decline in prevalence among participants in the younger age groups (ages 15–19 and 20–24) there has been increasing growth in HIV prevalence in the older age groups (ages 30–34 and 35–39), suggesting that they have been relatively neglected or not reached by HIV prevention programmes. Prevention of new HIV infections remains a major public health challenge for South Africa.³

It has been estimated that in a group of 108 low- and middle-income countries, about 1.5 million women who gave birth in 2006 were living with HIV.⁴ In South Africa it is estimated that in 2007, 707 948 pregnant women were tested for HIV and 290 000 pregnant women living with HIV needed ARVs for the sake of PMTCT.⁵ It was further estimated that nearly 200 000 children (aged 0–4 years) in South Africa were infected with HIV in 2007. Based on mortality data from 2005 it has been further estimated that each year at least 75 000 children in South Africa die before their fifth birthday.⁶ While there are a number of health challenges that contribute to these deaths, it is argued that HIV-related illnesses account for a large proportion and that

the most common route of HIV infection for children under the age of 5 years is through mother-to-child transmission (MTCT).

MTCT of HIV can occur during pregnancy, labour, delivery, and breastfeeding, especially mixed methods of infant feeding.⁷ Well over 90% of new HIV infections among infants as well as young children may occur through MTCT. Without any interventions, between 20% and 45% of infants may become infected with HIV through MTCT, with an estimated risk of 5–10% of infections occurring during pregnancy, 10–20% during labour and delivery, and 5–20% through breastfeeding.⁸

Nonetheless, the overall risk of HIV transmission can be possibly reduced to less than 2% of births to HIV-positive mothers if a package of evidence-based interventions are made available and used by HIV-positive pregnant women and mothers. The package of interventions is based on the United Nations' four-pillar strategy for PMTCT. The first three of these strategies are prevention focused, while the fourth focuses on ongoing care and treatment for HIV-positive mothers and HIV-exposed infants and children. The latter approach highlights the protracted nature of PMTCT and highlights the need for commitment to a long-term, comprehensive and integrated response.⁹ The four pillars of a PMTCT-response are:¹⁰

1. Primary prevention of HIV infections among individuals of child-bearing age.
2. Prevention of unintended pregnancies among HIV-positive and HIV-negative females of child-bearing age.
3. Prevention of MTCT of HIV.
4. Provision of appropriate treatment, care and support for women living with HIV to include children and families.

The package of available evidence-based services also highlights the protracted and complex nature of PMTCT and the importance of a comprehensive and integrated response. The following are examples of the evidence-based services recommended¹¹:

1 UNAIDS & WHO, 2008
 2 UNAIDS & WHO, 2008
 3 Department of Health [South Africa], 2008a
 4 UNICEF, 2009
 5 WHO, UNAIDS & UNICEF, 2008
 6 Bradshaw et al., 2008

7 Department of Health [South Africa], 2008b
 8 WHO & UNICEF, 2007
 9 WHO & UNICEF, 2007
 10 WHO & UNICEF, 2007
 11 WHO & UNICEF, 2007



- Health education
- Provider-initiated HIV testing and counselling
- Promotion and provision of male and female condoms
- Couples and partner counselling
- Screening for HIV
- Attention to gender-based violence
- Obstetric care
- Nutritional support and provision of supplements
- Counselling and support concerning infant feeding
- Family planning
- Birth preparedness
- Provision of ARV prophylaxis
- ARV treatment and adherence
- Psychological support
- Tetanus vaccinations, STI screening and treatment, and TB screening and treatment.

Therefore, the success of PMTCT programmes rests on expanding access to services and ensuring that these services are used frequently.¹² Success also rests on providing adequate information to the general population and relevant service providers and on providing adequate and on-going support to HIV-positive mothers once they have given birth. The potential for PMTCT to reduce the risk of HIV transmission to less than 2% of births to HIV-positive mothers underscores the importance of a communication strategy that reaches all relevant stakeholders.

3.2 PMTCT in South Africa: Operational and political history

In 1994, a study by researchers in France and the USA collaborated on a major study - code-named ACTG 076 – found that mono-therapy with AZT dramatically reduced the risk of MTCT.¹³ Due to the cost of AZT at the time and the South African government's resistance to its use, it

took time before a national PMTCT programme would be implemented in South Africa. In 2001, the Treatment Action Campaign (TAC), Save Our Babies, and the Children's Rights Centre took the government to court. The court found in favour of the organisations and subsequently ordered the government to develop a comprehensive national programme for PMTCT.¹⁴ Due to these operational and political factors, the PMTCT programme (conceptualised in 2001) was implemented at pilot sites in 2001, but only nationally in 2002.¹⁵ It has been estimated that 35 000 babies were born with HIV because a feasible and timely ARV programme was not implemented in South Africa.¹⁶ This underscores the imperative for coherent policy and implementation of a sustained PMTCT programme with a strong communication strategy capable of mobilising uptake, broad-based community support, retention and quality interpersonal communication among health workers and with their clients.

Currently the national PMTCT programme is available in 3 000 primary healthcare facilities across the country.¹⁷ The programme offers a package of services that together contribute to the reduction of MTCT. Despite this, only 60% of pregnant women who tested positive received Nevirapine during the 2005/06 financial year.¹⁸ It is estimated that 290 000 pregnant HIV-positive women in South Africa are in need of ARVs for PMTCT.¹⁹ In 2002, estimated HIV prevalence among children ages 2–14 years was 5.6% — dropping to 3.3% by 2005. Despite this decrease, findings from 2005 confirm high HIV prevalence among South African children. HIV prevalence among 2- to 4-year-olds is 4.9% for males and 5.3% for females, and prevalence among 5- to 9-year-olds is 4.2% for males and 4.8% for females.²⁰

South Africa continues to have one of the highest under-five mortality rates.²¹ In 2007 it was estimated that the under-five mortality rate in South Africa was 59 deaths per 1 000 live births. Out of 84 countries described as less

¹² WHO & UNICEF, 2007

¹³ Connor et al., 1994

¹⁴ Coovadia, 2009

¹⁵ Department of Health [South Africa], 2008b

¹⁶ Chigwedere, Seage, Gruskin, Lee & Essex, 2008

¹⁷ Department of Health [South Africa], 2008b

¹⁸ Department of Health [South Africa], 2008b

¹⁹ WHO, UNAIDS & UNICEF, 2008

²⁰ Shisana, Rehle, Simbayi, Zuma, Connolly, Jooste et al., 2005

²¹ Coovadia, 2009

developed, South Africa has the fourteenth-highest under-five mortality rate.²² While there is evidence to show that PMTCT programmes are acceptable, feasible and cost-effective, programmes have not been implemented widely in low- and middle-income countries.²³ There is an urgent need for renewed efforts to offer quality PMTCT services in the South African context and to ensure that these services are offered routinely and that rates of uptake increase.

Ongoing research in Khayelitsha (South Africa) reported that the vertical transmission of MTCT in 2007 was 3.5% and that the acceptance rate for HIV testing was nearly 100%. These findings provided evidence that PMTCT programmes in resource-constrained settings can reach all mothers who need the services and can bring about a reduction in MTCT.²⁴

When there was no indication that the Department of Health (DoH) intended to amend their 2007–2011 policy and guidelines in accordance with new scientific advances in PMTCT, activists began a concerted campaign demanding the introduction of dual therapy (i.e., AZT and NVP). Finally, in late January 2008, the DoH officially approved the shift to this treatment regimen. However, the DoH ignored demands to add lamivudine (also called 3TC) to AZT for the 7-day postpartum course; known as ‘cover the tail’ strategy, the addition of 3TC is recommended by WHO.²⁵ Also ignored were recommendations (made in keeping with USA and European guidelines and practices) that HIV-positive pregnant women should begin ART when their CD4 cell count reaches 350, instead of equal to or less than 200 as set out in the DoH 2007–2011 policy and guidelines document.²⁶

Since the introduction of dual therapy in the Western Cape Province, the uptake of treatment by women has increased and infant MTCT has decreased.²⁷ The DoH now plans to have dual therapy available to 80% of pregnant women by 2009/10, thereafter increasing rollout to 95%.²⁸ These and other recent pledges to scale up PMTCT are detailed in ‘Department of Health — Strategic Plan 2009/10–

2011/12.’

It should be noted that the DoH’s statistics on PMTCT need to be read with a measure of caution. A recent study found that “data collected and reported in the public health system across three large, high HIV-prevalence districts was neither complete nor accurate enough to track process performance or outcomes for PMTCT care.”²⁹

22 Save the Children, 2009

23 WHO, 2006

24 Booth, 2008

25 Bateman, 2008

26 Bateman, 2008

27 Department of Health [South Africa], 2007: 13

28 Department of Health [South Africa], 2009b

29 Mate, Bennett, Mphatswe, Barker & Rollins, 2009: 1



4. Relevant HIV/AIDS policies in South Africa

4.1 The HIV and AIDS and STI Strategic Plan for South Africa 2007–2011

The national strategic plan identifies HIV prevention and treatment as two of its priority areas. Prevention goals specific to PMTCT are to:

- “Broaden existing [prevention of] mother-to-child transmission services to include other related services and target groups.
- Scale up coverage and improve quality of PMTCT to reduce MTCT to less than 5%.”³⁰
- The national strategic plan’s treatment goals involve making provision for the special treatment needs of women and children:
- “Decrease HIV and AIDS-related maternal mortality through women-specific programmes.
- Determine the HIV status of infants, children and adolescents as early as possible.
- Provide a comprehensive package of services that include wellness care and ART to HIV-affected, -infected and -exposed children and adolescents.”³¹

4.2 Policy and guidelines for the implementation of PMTCT

In line with international standards, the ‘SA National DoH Policy on PMTCT, 2008’ recognises the need for a comprehensive, four-pronged response to reduce MTCT of HIV³²:

1. Primary prevention of HIV, especially among women of childbearing age.
2. Prevention of unintended pregnancies among HIV-positive women.
3. Prevention of HIV transmission from an HIV-positive woman to her infant.
4. Provision of appropriate treatment, care and support to women with HIV, their children and families.

The following basic package of services is available for the prevention of MTCT:

- Routine offers of VCT to pregnant women; those testing HIV-positive to be screened for TB, have a CD4 cell count taken, and if appropriate, receive an ARV regimen for PMTCT short-course or else HAART.
- In keeping with new scientific evidence, and after considerable pressure from lobbyists (see section 3.2), the DoH replaced single-dose NVP treatment (as specified in the national strategic plan) with dual therapy.³³ The process for pregnant women presenting at DoH clinics is:
 - HIV-positive pregnant women with a CD4 cell count ≤ 200 to be initiated onto HAART.
 - Pregnant women not eligible for HAART (CD4 cell counts over 200 or count unknown) to receive a dual therapy regimen entailing AZT from their 28th week of pregnancy until labour, and a single-dose NVP during labour.
 - Infants of HIV-positive mothers to get a single dose of NVP, followed by AZT for 28 days (in the case of infants whose mothers received suboptimal HAART or PMTCT) or for 7 days (in the case of infants whose mothers received optimal HAART or PMTCT).
- Counselling and support for infant feeding.
- Safe obstetric practices.
- Provision of formula feed to those who chose to use replacement feed and for whom it is affordable, feasible and sustainable.

The policy further prioritises effective implementation through³⁴:

- Supportive leadership;
- The right to information;
- Effective communication;
- Effective partnerships;
- Creating a supportive environment for PMTCT;
- Tackling inequality and poverty;
- Strengthening *and* integrating service delivery;
- Ongoing training of healthcare workers using a PMTCT

30 Department of Health [South Africa], 2007: 11

31 Department of Health [South Africa], 2007: 12

32 Department of Health [South Africa], 2008b

33 Department of Health [South Africa], 2007

34 Department of Health [South Africa], 2008b

module that has been updated to include dual therapy, infant feeding, and data management in the PMTCT programme.

To realise the principle of effective communication and the right to information, the national PMTCT programme aims to develop a comprehensive integrated communication strategy. The strategy involves the use of mass media campaigns and effective comprehensive communication methods to disseminate information about PMTCT to target groups, including service users and providers, the public at large, and community leaders. The programme also aims to strengthen community-based outreach through household and door-to-door activities to increase awareness of PMTCT services.³⁵

4.3 Department of Health — Strategic Plan 2009/10–2011/12

The DoH's current strategic plan outlines a number of priorities to strengthen the national PMTCT programme. Communication is recognised as important for promoting policy and buy-in in support of government programmes. The strategic plan describes intentions to conduct 13 ministerial *izimbizos* with different communities where members will be able to interact directly with the Minister of Health. In addition, the strategic plan expresses commitment to strengthening partnerships with all stakeholders, including grassroots structures. For example, 27 000 community HIV/AIDS caregivers will receive stipends by the end of 2009/10. In this way, the DoH aims to revive constructive grassroots-level participation in health service delivery.

The strategic plan also aims to accelerate the implementation of the HIV and AIDS national strategic plan and to strengthen the implementation of the national PMTCT programme.³⁶ In line with Millennium Development Goal No. 4, the DoH will ensure:

- An increase in the number of those HIV-exposed infants

who receive dual-therapy for PMTCT.

- An increase in the proportion of pregnant women who are tested for HIV.
- An increase in the number of pregnant women who are placed on dual-therapy.
- An increase in the number of eligible pregnant women who are placed on HAART.

Minister of Health Dr Aaron Motsoaledi held a press conference in Tshwane on 18 May 2009 to outline health priorities. He stated: "Within the next two weeks we shall officially launch the Prevention-of-Mother-to-Child-Transmission (PMTCT) Acceleration Plan; this will help us to achieve the Health Millennium Development Goals, which include maternal mortality, infant mortality and combating HIV and AIDS, malaria and TB, amongst others."³⁷

And, in his June 2009 budget speech,³⁸ Dr Motsoaledi pledged:

We will work with provinces in 2009/10 to ensure that 80% of HIV-exposed infants receive ARVs for PMTCT (based on dual therapy). This figure will increase to 95% over the two years of the medium term expenditure framework (2010/11–2011/12). The proportion of pregnant women who are tested for HIV will be increased from 80% in 2009/10, to 95% in 2010/11 and 2011/12.

To strengthen the prevention of mother-to-child transmission of HIV, 80% of pregnant women who are eligible will be placed on ARV prophylaxis based on dual therapy in 2009/10.

This figure will increase to 95% in the outer two years of the MTEF period; 30% of eligible pregnant women will be placed on HAART in 2009/10. This service will be expanded to cover 50% of pregnant women in 2010/11, and 75% in 2011/12.

4.4 SANAC Programme Implementation Committee meeting

³⁵ Department of Health [South Africa], 2008b

³⁶ Department of Health [South Africa], 2009a

³⁷ Department of Health [South Africa], 2009c

³⁸ Department of Health [South Africa], 2009b



In February 2009, during a SANAC Programme Implementation Committee (PIC) meeting, Dr Nonhlanhla Dlamini announced the PMTCT accelerated roll-out plan for South Africa. SANAC endorses the DoH's strategic plan to strengthen the implementation of the national PMTCT programme.³⁹ The PMTCT accelerated roll-out plan will include developing a comprehensive monitoring system and a community mobilisation programme. Existing community healthcare workers will be used to help monitor the clients enrolled in PMTCT programmes. The programme will take place both within clinics and within the broader community. Training will commence in Zululand and then extended nationally.⁴⁰ During the PIC meeting, Deputy Chairperson Mark Heywood commented that the accelerated roll-out plan provides an opportunity for the DoH, SANAC, and civil society to work together around social mobilisation. He went on to request that a communication campaign be integrated into the accelerated roll-out plan.⁴¹

39 South African National AIDS Council (SANAC) Programme Implementation Committee (PIC), 2009

40 Booth, 2009

41 SANAC PIC, 2009

5. Communication in the context of HIV and AIDS

5.1 Communication theories and approaches in the context of HIV/AIDS

The HIV/AIDS epidemic is driven by a complex set of factors in South Africa, which includes social, cultural, historical, political, economic and gendered factors. HIV and AIDS also touch on sensitive issues such as people's sexuality and identity. It challenges notions of morality and questions our accepted understandings of gender, disease and death. The complexity of this disease renders communication approaches that are based on the assumption of a rational individual who makes choices in a social vacuum both redundant and ineffective.^{42,43,44}

Models of information transmission and persuasion tend to dominate the design of strategic communication in the field of health. Communication, from this perspective, involves delivering a predetermined message to a particular group of individuals in an attempt to persuade them to behave in a desired way. Such an approach is one-sided, top-down, persuasion-oriented, and tends to view communities as homogenous objects of change.⁴⁵ This approach is also critiqued for promoting a paternalistic view of development. For example, such approaches implicitly assume that the knowledge of the organisation/agency/government developing the message is always right, while those receiving the message are assumed to be ignorant.⁴⁶

What is needed in the context of HIV and AIDS is an approach to communication that takes seriously the social context in which people negotiate their lives and that recognises the need for long-term and sustained efforts that engage local communities in the development of contextually relevant and appropriate responses. Such an approach promotes collective discussion and debate in addition to individual reflection and self-awareness, and simultaneously attempts to address social, cultural, economic and political factors in an attempt to create health-enabling

contexts.^{47,48,49,50} An integrated and comprehensive approach to communication emphasises, firstly, a process of dialogue and collective action, and, secondly, aims for social outcomes alongside individual outcomes.⁵¹

Four theories and/or approaches have challenged the top-down and persuasive types of approaches to communication⁵²:

- **Dependency theory:** This argues that the problems of many underdeveloped countries are political rather than the outcome of a lack of knowledge or information, and recognises a need to bring about structural change rather than targeting the individual.
- **Participatory theories and approaches:** This challenge the paternalistic approach of dominant communication strategies, arguing for the active ownership and participation of community members and the use of interpersonal communication (small media) in contexts where mass media and technology can be experienced as alienating and foreign.
- **Media advocacy:** Rather than aiming to directly influence audiences, media advocacy aims at creating public debate around public health issues. It focuses on social themes and argues that social conditions, rather than the behaviour of individuals, should be the focus of interventions. The focus of media advocacy is therefore socio-political change and inequity.
- **Social mobilisation:** This recognises the importance of mobilising social actors to become increasingly aware of a particular programme and to eventually assist in the delivery of services. The focus is on the mutual benefits to partners and the decentralisation of structures. Social mobilisation involves an appeal for community participation rather than appealing to individuals to assist.

All these theories and approaches bring something of value to the communication field and it is suggested that a communication strategy be devised to include the following key points of convergence between the theories and approaches⁵³:

42 Vincent, 2006
 43 Melkote, Muppide & Goswami, 2000
 44 Airhihenbuwa, Makinwa & Obregon, 2000
 45 Figueroa, Kincaid, Rani & Lewis, 2002
 46 Waisbord, 2001

47 Vincent, 2006
 48 Scalway, 2001
 49 Melkote, Muppide & Goswami, 2000
 50 Airhihenbuwa, Makinwa & Obregon, 2000
 51 Figueroa et al., 2002
 52 Waisbord, 2001
 53 Waisbord, 2001



- The need for political will;
- A ‘toolkit’ conception of communication techniques, which are chosen based on their appropriateness in certain contexts under certain conditions (for example, conventional approaches are appropriate as a short-term strategy when large numbers of people have to be reached quickly);
- Integration of ‘top-down’ and ‘bottom-up’ approaches. This involves government commitment and community mobilisation;
- Integration of multimedia and interpersonal communication;
- Integration of personal and environmental approaches.

5.2 Communication for social change: An integrated approach

The communication-for-social-change approach has been recognised as having integrated various aspects of the different theories and approaches into an effective communication strategy.⁵⁴ Such a strategy is based on the following principles and approaches⁵⁵:

- Community ownership to improve sustainability of social change;
- Empowering, horizontal communication that gives voice to members of the community;
- A view of community members as agents of their own change rather than objects of change;
- Emphasis on debate and the negotiation of issues that are meaningful to the community.

Change extends beyond individual behaviour to social norms, policies, culture and other contextual factors that undermine a health-enabling environment.

5.3 JHU’s social ecology model

Johns Hopkins University (JHU) uses a strategic commu-

nication approach that combines different mediums and modes (for instance, mass media, community messaging, interpersonal communication and advocacy) to bring about behavioural and social change. A strategic approach recognises that in order to influence change, communication needs to operate at multiple levels: societal, community, social network and individual. To this end, JHU adopts a conceptual framework based on the social ecology model, illustrated below.⁵⁶

As noted in the 2008–2009 strategic plan for the JHU Programme in South Africa⁶³:

Change at one level may be facilitated or obstructed by another level. For example, a woman may choose to make use of prevention-of-mother-to-child-transmission services such as formula feeding. However, this may be impacted upon if her partner is aware and supportive of her status and thereby enables the use of formula feed, or where formula feeding may be culturally regarded as not being appropriate this may also impede usage. The ability to access PMTCT services will be further influenced by the societal policy and legislative levels where the availability or lack of PMTCT services or the cost of accessing these resources can impede usage as a result of poverty that places this beyond the realm of those most in need.

54 Waisbord, 2001

55 Scalway, 2002

56 USAID/Johns Hopkins University/JHU Programme in South Africa, 2009: 14.

6. Communication theories and approaches in use in PMTCT programmes

A number of different communication theories or approaches have been used in the context of PMTCT across sub-Saharan Africa, as outlined in the next sections.

6.1 Communication for development and the ACADA process

Based on pilot programmes in Botswana and Rwanda, UNICEF encourages use of the communication-for-development-planning approach, which involves developing PMTCT communication strategies around advocacy, social mobilisation and programme communication. Multisectoral teams use the ACADA (assessment, communication analysis, design and action) process to develop integrated PMTCT communication strategies for advocacy, social mobilisation and programme communication.

6.2 Communication for development in the South African context

In 2002 the Government of South Africa, in collaboration with the Centers for Disease Control and Prevention (CDC) in the United States, tested the communication-for-development approach, based on the ACADA planning process, and concluded that this was the best option for South Africa. The approach is collaborative and meant to ensure community participation in the development of context-specific strategies for each province. Training was subsequently provided to multisectoral teams.

The PMTCT communication strategy aims to⁵⁷:

- Increase access to condoms in non-traditional sites;
- Decrease stigma in communities in order to increase support and care;
- Increase access to VCT in non-traditional sites;
- Increase exclusive infant-feeding choices through family counselling aimed at establishing new community norms;
- Encourage up-take of ANC services;
- Mobilise stakeholders such as traditional healers to increase support for PMTCT and VCT services through community dialogue.

In developing this review attempts to locate follow-up documentation of this programme (or evaluations of its outcomes) proved unsuccessful. This highlights the importance of ongoing monitoring and evaluation during the development of future PMTCT communication strategies. This will ensure that lessons learned are documented and can feed back into and contribute towards the development of appropriate communication strategies. For example, it would be useful to know what the outcomes of the 2003 collaboration between the government and the CDC were and what lessons were learned during the process.

6.3 Behaviour change communication (BCC)

PEPFAR has been actively involved in designing and implementing behaviour change communication (BCC) PMTCT strategies in various countries, including South Africa.⁵⁸ BCC strategies using information, education and communication aim at promoting comprehensive HIV-prevention messages and delivering these messages to specific audiences with the aim of changing health-related behaviour.⁵⁹

6.4 Information, education and communication (IEC)

A number of programmes make use of locally developed information, education and communication (IEC) materials to raise awareness in the wider community about PMTCT and available services.^{60,61,62}

6.5 Community-oriented approach to behaviour change

Community-oriented behaviour recognises that behaviour change occurs in a context of social change. Information

58 PEPFAR, 2004
 59 PEPFAR, 2004
 60 Shetty, Maragwanda, Stranix-Chibanda, Chandisarewa, Chipara et al., 2008
 61 Perez, Mukotekwa, Miller, Orne-Glieman, Glenshaw, Chitsike et al., 2004
 62 IMAU & CDC [Uganda], 2003



is placed within communities to facilitate dialogue, debate and collective action. Within the context of PMTCT, this approach recognises the importance of creating widespread awareness about the range of behaviours that are necessary for PMTCT. For example, the necessary obstetric practices should not be communicated only to professional health practitioners, but also to traditional birth attendants (TBAs), families and the wider community.⁶³

6.6 Targeted education messages and communication

Evaluative research shows the importance of targeted education messages. Areas of misconception about HIV/AIDS and PMTCT need to be identified so that local health authorities can design and target appropriate messages to fill gaps in knowledge.⁶⁴

6.7 Interpersonal communication (IPC)

Some PMTCT programmes argue for investment in interpersonal communication (IPC), where IEC materials are used to support this rather than using the materials as the main method of communication.⁶⁵

6.8 Communication for social change

A number of PMTCT programmes make use of communication for social change. Some programmes argue for targeted education messages to be combined with techniques promoting communication for social change. Such an approach acknowledges the importance of filling gaps in knowledge as well as addressing the social, cultural and economic contexts that impact on behaviours such as infant-feeding practices and sexuality.⁶⁶ Communication for social change recognises the need for community ownership; the importance of horizontal communication rather than top-down, vertically transmitted messages and the importance

of seeing people as agents of change rather than as objects of change. This approach values dialogue and debate over and above persuasion and aims to support behaviour change by addressing the social norms, cultural practices, and policies that may constrain health-enabling practices.⁶⁷

63 Moore, 2003

64 Orne-Glieman, Mukotekwa, Perez, Miller, Sakarovitch, Glenshaw et al., 2006

65 UNICEF, 2002

66 Orne-Glieman et al., 2006

67 Scalway, 2002

7. Barriers to PMTCT

Evidence suggests that while many women may enrol in a PMTCT programme a number of factors result in a high drop-out rate. Coverage of key HIV interventions for women with children drops at the time of childbirth through to postnatal care. Statistical data of healthcare coverage in South Africa showed that while 94% of women who attended ANC at least once, only 73% attended four or more times, and only 27% attended ANC by the time their infant was 20 weeks old. This shows a cascade of diminishing service use and highlights that there are many missed opportunities for PMTCT, especially through follow-up services. This gap in coverage is influenced by the availability of appropriately skilled healthcare workers (a quality gap). Moreover, hidden in the national averages are clear disparities between the rich and poor, public and private healthcare sectors, and between rural and urban settings (an equity gap). For example, skilled attendance during birth is one-third lower among the poorest families when compared to richer families.⁶⁸

The following sections outline the barriers identified as inhibiting the up-take of PMTCT services and causing loss to follow-up in a number of African countries.

7.1 Societal barriers

7.1.1 Healthcare infrastructure and shortage of staff

- A shortage of appropriately trained and skilled health workers impacts on general service delivery.^{69,70,71,72} Research conducted at a clinic in the rural Eastern Cape Province in South Africa, for example, reported that after PMTCT practices were integrated into the clinic no additional staff were allocated to the clinic. As a result the clinic was staffed by nurses and nurse assistants who reported that they did not have the capacity to provide quality services.⁷³
- A lack of trained lay counsellors has been found to in-

hibit the number of people who receive services like VCT.^{74,75,76,77} South African research has indicated that the North-West and Eastern Cape provinces are still struggling to integrate lay counsellors into their VCT programmes. It is not surprising, therefore, that these two provinces report low percentages of HIV testing in the ANC setting (14% testing uptake the North-West, and 34% in the Eastern Cape).⁷⁸ In comparison, figures from Gauteng, KwaZulu-Natal and the Western Cape provinces, which prioritise the utilisation of lay counsellors, reveal the smallest drop off between the first ANC visit and women accepting to be tested for HIV.⁷⁹

- Research in South Africa indicates that healthcare workers who offer family-planning services are seldom trained in HIV/AIDS care, which in turn points to lack of an integrated approach to healthcare provision. This research also indicated a high turnover of staff, which means that expertise around family planning is not always sustainable.⁸⁰
- Poor working conditions for healthcare workers will lead to low retention of staff in resource-poor contexts.⁸¹ In South Africa, a high turnover of staff may be due to poor incentives, infrastructure and remuneration.⁸²
- Inadequate spaces for confidential counselling and private disclosure, and a small number of sites in widely dispersed populations have been found to inhibit the uptake of PMTCT services.^{83,84,85} Research in South Africa found that a lack of privacy in delivery rooms may prevent a woman from disclosing her HIV status when asked by a healthcare worker.⁸⁶ An early evaluation of the PMTCT programme in South Africa found that in some provinces there is insufficient space dedicated to coun-

68 Department of Health [South Africa] et al., 2008b
 69 Department of Health [South Africa] et al., 2008b
 70 WHO, 2007
 71 Tearfund, 2008
 72 Burke, 2004
 73 Skinner, Mfecane, Henda, Dorkenoo, Davids & Shisana, 2003

74 WHO & UNICEF, 2007
 75 Perez et al., 2004
 76 WHO, 2007
 77 Doherty, McCoy & Donohue, 2005
 78 Doherty, Besser, Donohue, Kamoga, Stoops, Williamson & Visser, 2003
 79 Perez et al., 2004
 80 USAIDS, FHI & DoH 2005
 81 Manzi, Zachariah, Teck, Buhendwa, Kazima, Bakali et al., 2005
 82 USAID et al., 2005
 83 Skinner et al., 2003
 84 WHO & UNICEF, 2007
 85 WHO & UNICEF, 2007
 86 Doherty et al., 2005



selling. In some counselling sites, rooms often serve dual purposes; a storeroom, for example, may be used as a counselling room, with frequent disruptions to the counselling process.⁸⁷

- Although PMTCT programmes might be integrated into antenatal services, the different services may be housed in different buildings, making HIV-positive women attending certain services vulnerable to stigmatisation.⁸⁸

7.1.2 Healthcare workers' poor attitudes and interactions with clients

- Clients who are fearful of healthcare workers are not likely to return for follow-up sessions. In a study in Cote d'Ivoire, women reported being afraid of the staff. For example, an HIV-positive mother who had decided to keep her baby was afraid of being chased away by the doctors if she returned to the clinic. Another woman described how she could not find the right staff member during a follow-up visit and was too afraid to ask anyone in case she got reprimanded in front of the other pregnant women. This woman never returned for further follow-up sessions.⁸⁹
- Research suggests that the South African healthcare system is characterised by highly coercive relationships between programme providers and service users, particularly between nurses and their clients. Findings reveal that HIV-positive women who chose to have a child ran the risk of being judged by the healthcare worker.⁹⁰ Two-thirds of the research participants from an informal settlement in the Western Cape (South Africa) reported that a healthcare worker had advised them to formula feed; these women had not received information about different infant-feeding options. Other studies found that health workers influenced 80% of women's infant-feeding choices. This suggests biased and subjective counselling, leaning in the direction of formula feeding.⁹¹ It also suggests that interpersonal communication in a medical setting is an important site for communication interventions given this powerful influence (this is discussed be-

low, under the heading 'strengthening PMTCT through interpersonal communication').

- Nurses are primarily schooled in a medical discourse, where value is attached to compliance to evidence-based medical interventions rather than to individual rights. For example, research in Pietermaritzburg (South Africa) showed that women who, for whatever reason, choose not to breastfeed in contexts where exclusive breastfeeding is promoted, run the risk of being discriminated against and judged by nurses providing information and advice.⁹² Some counsellors observed in research conducted in Durban (South Africa) were found to be judgmental and coercive when counselling mothers about breast-feeding.⁹³ Staff members have been found to take over decision-making for women. For example, healthcare staff may force women into HIV testing for their infants and coerce women into medically preferred decisions. Paternalistic and punitive approaches have also been reported; for instance, some women were denied ARV treatment for not remembering the names of certain medications while being prepared for treatment.^{94,95,96}
- Support-group leaders may use their position of power or assume an advisory bio-medical approach (again, with preferred outcomes) to discourage HIV-positive women who want a child from becoming pregnant. In these cases options are not discussed with the women, leaving them ill informed. Research in Kenya found that healthcare workers gave directive counselling for HIV-positive women that discouraged women from having children.⁹⁷
- Research in a resource-poor setting in the Eastern Cape Province (South Africa) found that clients feared a lack of confidentiality among counsellors.⁹⁸
- In faith-based organisations (FBOs), limited extensive family-planning counselling might not be offered due to religious perspectives on sexuality.⁹⁹

87 Doherty et al., 2003
 88 Thorsen, Sunby & Martinson, 2008
 89 Painter, Diaby, Matia, Lin, Sibailly, Kouassi et al., 2004
 90 London, Orner & Myer, 2008
 91 Petrie, Schmidt, Schwarz, Koornhof & Marias, 2007

92 Seidel, 2000
 93 De Paoli, Mkhwanazi, Richter & Rollins, 2008
 94 Kgwete, 2008
 95 Scorgie & Crankshaw, 2008
 96 Stevens, 2008
 97 Baek & Rutenberg, 2005
 98 Peltzer, Mosala, Shisana, Nqeketo & Mngqundanis, 2007
 99 Rutenberg & Baek, 2004

7.1.3 Poor quality of counselling and information

- The uptake of testing and PMTCT services is low in sites where counselling is of poor quality.^{100,101}
- Poor-quality counselling often results in the transmission of incomplete knowledge, which can impede the effectiveness of PMTCT programmes.^{102,103} Research in South Africa found that while the communication skills of counsellors were good, the mother's knowledge remained low post-counselling. Observations of counselling sessions found that inaccurate beliefs were corrected by counsellors in only 32% of the sessions. Additionally, the counsellors did not adequately assess which infant-feeding practice was most appropriate for the client they were counselling: only 12 of 34 clients were told about the risks of MTCT and only three of these clients were asked whether they had access to clean water. Only 13 of the 34 clients were asked if they had a partner and if they knew their partner's HIV status. While the counsellor explained the advantages of disclosure, only seven of the clients were encouraged to make a decision during the session. The advice given to mothers about their different infant-feeding options was patchy and they were often left to make decisions on their own. On the whole, only 9% of the mothers were asked if they knew the meaning of exclusive breastfeeding, and not one was asked if they thought it was a feasible option. Only seven out of 15 HIV-positive mothers who chose to formula feed were given instructions on where to collect formula supplies; five of these mothers were given the opportunity to reconsider the feeding option; and only five were asked if they had previously prepared formula and then provided with instructions. The counsellors did not discuss with the mothers how they would explain the decision to not breastfeed to their partner or family.¹⁰⁴
- Another study in the Eastern Cape Province (South Africa) found that while knowledge about MTCT was relatively high, knowledge about PMTCT was low. There was very little evident knowledge about exclusive breastfeed-

ing and formula feeding.¹⁰⁵ Similar findings emerged from research conducted in Botswana, Kenya, Malawi and Uganda. Here it was found that 70% of health workers were unable to correctly describe the risks of breastfeeding after training; infant-feeding options were only mentioned in 48% of the counselling sessions, and discussed in detail in only 5.5% of these sessions, of which 54.3% were rated as poor-quality sessions by the observer.¹⁰⁶

- In another study that explored the effect of a PMTCT programme on infant feeding in South Africa, none of the healthcare workers could correctly estimate the risk of spreading HIV through breastfeeding and many reported feeling confused about what they should tell mothers.¹⁰⁷
- It has been suggested that the avoidance of the topic of infant feeding in PMTCT counselling might reflect the counsellors' own confusion about infant-feeding practices.¹⁰⁸ Some mothers might experience being told that they can breastfeed — but for only six months — as contradictory and confusing.¹⁰⁹ Low levels of general knowledge about MTCT and breastfeeding in particular have also been found in rural India, rural Zimbabwe and Nigeria.^{110,111,112} Further research in Botswana confirmed significant gaps in the information given by counsellors about PMTCT.¹¹³
- Uncertainty about the option to breastfeed has also served to increase the power and influence of health workers who act as gatekeepers to knowledge and certain resources (like formula feeding).¹¹⁴
- Research in South Africa indicated that despite IUD contraceptive use being safe for HIV-positive women, some family-planning service providers would not administer an IUD because they believed it increased the risk of an

100 WHO & UNICEF, 2007
 101 Ogudele & Coulter, 2003
 102 Chopra, Doherty, Jackson & Ashworth, 2005
 103 Chopra & Rollins, 2008
 104 Chopra et al., 2005

105 Peltzer et al., 2007
 106 Chopra & Rollins, 2008
 107 Chopra, Piwoz, Songwana, Schaay, Dunnett & Sadlers, 2002
 108 Coovadia & Bland, 2007
 109 Thorsen et al., 2008
 110 Gupta, Lhewa, Vishwanath, Jacob, Parameshwani, Radhakrishnan et al., 2007
 111 Orne-Glieman, Mukotekwa, Perez, Miller, Sakarovitch, Glenshaw & Engelsmann, 2006
 112 Adeneye, Mafe, Adeneye, Salami, Brieger, Titiloye et al., 2006
 113 Baek, Creek, Jones, Apicella, Redner & Rutenberg, 2009
 114 Doherty, Chopra, Nkoki, Jackson & Greiner, 2006



STI, including HIV. This highlights the need for, and perhaps lack of, refresher training among counsellors and healthcare workers.¹¹⁵

- Research in Botswana found that counsellors had different ideas about the choice of what information was crucial to communicate to HIV-positive pregnant women.¹¹⁶ When asked what was important, there were varied responses and agreement about only two areas: the evaluation of ARV treatment and using condoms. Disturbingly, only 30% of the nurses and midwives interviewed thought that PMTCT should be addressed in a counselling session with HIV-positive pregnant women, and only 11% thought infant formula feeding should be discussed. While the counsellors fared better, there was still reason for concern: while 69% of the counsellors thought PMTCT should be addressed, only 11% thought that infant feeding should be discussed.¹¹⁷
- Respondents in a study in Uganda suggested that the trainers responsible for running PMTCT-information workshops may not have the appropriate skills and may use language and terminology that is unfamiliar to the target audience, who may therefore not understand important aspects of PMTCT.¹¹⁸

7.1.4 Inadequate family-planning services and counselling

- Research from South Africa has suggested that family-planning policies may not be adequately sensitive to gender-related issues and that attention to individual women — as opposed to men and couples — may be comparatively overemphasised.¹¹⁹
- Research in South Africa reported inadequate male involvement in family planning. Men are likely to feel intimidated by the large number of women attending regular family-planning sites and there is a lack of male-friendly family-planning sites and programmes.¹²⁰
- Promising research from Kenya found that the majority

of HIV-positive women (72%) indicated that they could talk to their male partner/husband about HIV. The vast majority of HIV-negative women (93%) indicated that they could talk to their male partner/husband. HIV status, therefore, may have implications for family planning, as disclosure of status is needed to initiate a discussion of whether or not to have a child.¹²¹

- Research in Uganda found that 73% of individuals practicing pregnancy-risk behaviour did not want a child and were at high risk for an unwanted pregnancy; of 42% of participants who were sexually active, 18% expressed a desire to have a child.¹²²
- Research in Kenya found that most of the participants who had been sexually active in the last month had unmet family-planning needs. Research in Uganda and Kenya found the following reasons for wanting to have a child: wanting to leave a lineage, wanting to have either a boy or girl child, not yet having a child, wanting to add siblings to the family, and wanting support in old age.¹²³ Contraception has been shown to have contributed to the reduction of infant infections.^{124,125} In Kenya, men were four-times more likely than women to want a child.¹²⁶
- Research in a number of developing countries found that PMTCT sites often miss opportunities to provide clients with family-planning services. In Zambia, for example, it was found that slightly more than 50% of the participants in the study received family-planning counselling at their first antenatal visit; however, this decreased to 38% among HIV-positive women and to 50% among HIV-negative women at the time of their six-month postpartum visit.¹²⁷
- Research also found that certain FBOs offering PMTCT services exclude comprehensive family counselling.¹²⁸
- Research in Lusaka (Zambia) found that at many sites 98% of women (both HIV-positive and HIV-negative) believed that HIV-positive women should not have a child.¹²⁹

115 USAID et al., 2005

116 Baek et al., 2009

117 Chopra et al., 2005

118 IMAU & CDC [Uganda], 2003

119 USAID et al., 2005

120 USAID et al., 2005

121 Baek & Rutenberg, 2005

122 Nakayiwa, Abang, Packel, Lifshay, Purcell, King et al., 2006

123 Nakayiwa et al., 2006

124 Reynolds, Janowitz, Wilcher & Cates, 2008

125 McCarraher, Cuthbertson, Kung'u, Otterness, Johnson & Magiri, 2008

126 McCarraher et al., 2008

127 Rutenberg & Baek, 2004

128 Rutenberg & Baek, 2004

129 Rutenberg & Baek, 2004

- Research in a number of developing countries has found that in settings with a low level of contraceptive use and high HIV prevalence the family-planning needs of HIV-positive women are typically dealt with by parallel family-planning services, but these services are often not tailored to meet the needs of HIV-positive women.¹³⁰

7.1.5 Inadequate integration of services

- PMTCT services like VCT are not routinely offered as part of maternal, newborn and child health (MNCH) services in developing countries: that is, PMTCT and ANC services are not adequately integrated.^{131, 132, 133} Even where the services are integrated this does not guarantee that family planning happens.¹³⁴ It was found in South Africa, that while facilities were providing routine MNCH services, additional follow-up care — including HIV-testing for infants and AIDS care — had not been integrated into PHC services at the majority of facilities.¹³⁵
- Findings from South Africa illustrate that PMTCT programmes are often integrated into healthcare systems that are already understaffed and over-pressurised, and as a result there are delays in aspects of implementation and in the training process.¹³⁶
- Although there is agreement in South Africa about the need to integrate family planning into PMTCT services due to the urgent need to deal with the family-planning needs of HIV-positive pregnant women, there is no agreement on the level of integration required. Service providers have argued that integration requires additional training concerning integrated service delivery. Achieving adequate integration of family-planning and HIV/AIDS services will involve a number of operational changes, including role definition, allocation of time, and developing an appropriate referral system.¹³⁷

7.1.6 Poor referral links

- Poor referrals within the healthcare system and between clinics have a negative impact on follow-up visits¹³⁸ and on the continuity of care between the different facilities.¹³⁹
- Geographical constraints often undermine the effectiveness of models like the family-oriented approach to PMTCT. For example, while it is possible to reach partners and children living together, it might not be possible to reach children who are not living with their biological families but with extended family members.¹⁴⁰
- In many rural areas there is a shortage of telephones; hence, healthcare workers often resort to communication by sending letters through public transport, which is unreliable.¹⁴¹ Poor communication between clinics impedes responses to emergency situations, complicates ongoing management, and limits important exchanges of information and referrals between sites.¹⁴²

7.1.7 Lack of communication within the healthcare system

- Poor communication of PMTCT-related policies to relevant healthcare workers will have a serious impact on the success and scaling-up of PMTCT programmes.^{143, 144, 145, 146} In South Africa, research reports that while family-planning and HIV/AIDS policies are communicated through workshops, training and meetings, some non-governmental service providers stated that they only discovered them accidentally or else downloaded them from the internet. This suggests that the private sector and NGO sector, which services 25% of health-service users in the country, are often excluded from policy training programmes.¹⁴⁷

130 Rutenberg & Baek, 2004

131 WHO, 2007

132 Burke, 2004

133 Rutenberg & Baek, 2004

134 Rutenberg & Baek, 2004

135 Doherty et al., 2003

136 Skinner, Mfecane, Gumede, Henda & Davids, 2005

137 USAID et al., 2005

138 WHO & UNICEF, 2007

139 Jones, Sherman & Varga, 2005

140 Tonwe-Gold, Ekouevi, Bosse, Toure, Kone, Becquet et al., 2009

141 Kagee, 2008

142 Kagee, 2008

143 WHO & UNICEF, 2007

144 Zambia Central Board of Health, 2004

145 Tearfund, 2008

146 Chopra & Rollins, 2008

147 USAID et al., 2005



- Most PMTCT programmes have focused almost entirely on PMTCT interventions, while fewer programmes have focused on primary prevention of HIV infections and the prevention of unintended pregnancies. It is suggested that this is partly due to the lack of clear policy and operational guidance on how these issues can be implemented within the context of the HIV epidemic.¹⁴⁸
- A combination of fear and misinterpretation of the UNAIDS/WHO/UNICEF guidelines on infant-feeding practices for PMTCT has led to reduced support of breastfeeding, despite evidence of its usefulness.¹⁴⁹
- A lack of up-to-date information results in health workers giving poor advice and poor-quality counselling on important PMTCT practices like exclusive breastfeeding.¹⁵⁰
- Healthcare workers report that they do not have guidelines to share with mothers to support them in their infant-feeding choices.¹⁵¹
- A resistance to meaningful collaboration between TBAs and medically trained healthcare workers is problematic in contexts where a large number of births take place at sites with TBAs.¹⁵²
- Financial constraints often hamper a woman's ability to rapidly cease breastfeeding, either because she will not have the money to purchase formula feed to replace breast milk (in contexts like Malawi¹⁵⁹), or because a clinic has run out of formula feed (which has been known to happen in the South African context¹⁶⁰). In South Africa, mothers may not have the finances to continue purchasing formula feed after six months, when the government stops providing free formula.
- Poor access to government grants denies women in many resource-poor contexts the means to attend follow-up sessions at a clinic.¹⁶¹
- Poor transportation infrastructure inhibits the up-take of services since people are unable to get to relevant treatment sites.^{162,163,164,165}
- A lack of telephones in rural areas impacts on referrals and general PMTCT delivery. A lack of telecommunications means that healthcare workers are not able to communicate with each other directly.^{166,167}
- A situation analysis of PMTCT services in the Eastern Cape Province (South Africa) found that in rural, underdeveloped areas there may be only one main road, while secondary roads are gravel or dirt, which are difficult to cross during rainy seasons. Under such circumstances, reaching a clinic may be difficult or impossible.¹⁶⁸

7.1.8 Poverty and infrastructure

- A lack of money in low-income areas prevents follow-up visits; for example, in contexts where transportation is needed to reach healthcare sites, people may not have the money to pay for it.^{153,154,155,156}
- Clients across sub-Saharan Africa may have to walk considerable distances to clinics due to a lack of money for transportation and the vast distances between sites.¹⁵⁷ A study in the Eastern Cape Province (South Africa) found that the average time it took a woman to reach a clinic was over one hour.¹⁵⁸
- Research in the Eastern Cape also found that scattered villages, lack of transportation networks and poor signage made giving and following directions to clinics difficult or impossible.¹⁶⁹

7.1.9 Overlooking the needs of youth

- Research in South Africa has indicated that the repro-

148 WHO & UNAIDS, 2007

149 Ogudele & Coulter, 2003

150 Coovadia & Bland, 2007

151 De Paoli et al., 2008

152 Manzi et al., 2005

153 Kagee, 2008

154 Skinner et al., 2003

155 Tearfund, 2008

156 Jones et al., 2005

157 WHO & UNICEF, 2007

158 Peltzer et al., 2007

159 Thorsen et al., 2008

160 De Paoli et al., 2008

161 Jones et al., 2005

162 Kagee, 2008

163 Tearfund, 2008

164 Skinner et al., 2005

165 Tlebere, Jackson, Loveday, Matizirofa, Mbombo, Doherty, Wigton, Treger & Chopra, 2007

166 Peltzer et al., 2007

167 Skinner, Mfecane, Gumede, Henda & Davids, 2005

168 Skinner et al., 2003

169 Skinner et al., 2003

ductive needs of youth are not adequately addressed in family-planning counselling. High levels of teenage pregnancy — despite educational campaigns and the availability of condoms — confirmed for many of the participants that HIV and AIDS had not affected the reproductive behaviour and choices of youth.¹⁷⁰

- In Tanzania, school pupils' knowledge about safe motherhood and MTCT was low, indicating a lack of interventions addressing reproduction at the teenage level. Many of the participants believed that complications during pregnancy and childbirth were due to pregnancy taboos and a result of not adhering to traditions. Knowledge about birth preparedness, risk factors and postpartum care was very low.¹⁷¹
- In South Africa, research has found that rural adolescents are less likely than their urban counterparts to successfully implement most PMTCT-related practices. It was also found that HIV stigma, family decision-making, and cultural norms surrounding infant feeding hampered adolescent mothers' attempts favouring PMTCT.¹⁷²

7.1.10 Cultural factors

- Research in the Eastern Cape Province (South Africa) shows that men often play a limited role during their partner's pregnancy and during childbirth and few attend clinic visits with their female partners — which has serious implications for women who will not attend PMTCT services without the consent of their partner.¹⁷³
- The phrase PMTCT implies that it is the woman's primary responsibility to prevent her infant from becoming HIV infected, which undermines efforts to increase male involvement in PMTCT.¹⁷⁴
- South African research suggests that TBAs may not be skilled in birthing practices favouring PMTCT and there is no standardisation for TBA training.¹⁷⁵ A large number of births across Africa are not attended by medically (and

PMTCT) qualified health professionals¹⁷⁶ and many occur at TBA sites (as found in Malawi¹⁷⁷).

- South African research found that in some cultures it is considered inappropriate for women to disclose their pregnancy to their mother-in-law until the pregnancy shows,¹⁷⁸ and research in Lesotho found a general taboo around public acknowledgement of pregnancy.¹⁷⁹
- Cultural taboos about talking about sex impact on the uptake of certain PMTCT services¹⁸⁰; for example, this will inhibit family planning or safer-sex discussions.
- Culturally accepted practices about infant feeding may make it very difficult for a woman to adhere to PMTCT-related feeding options. For example, in contexts where mixed feeding is an accepted practice, rapid cessation of breastfeeding is generally difficult for mothers to do.¹⁸¹ In Lesotho, for example, it is the man who decides on how long a child should be breastfed, and in some contexts this can be as long as two years¹⁸²; similarly, Tanzanian families placed pressure on women to introduce food to her infant.¹⁸³ In South Africa, a young mother is highly likely to be pressured by family regarding her infant-feeding choices.¹⁸⁴
- Social expectations regarding a woman's childbearing role influence decisions about childbearing. Pressure from male partners/husbands, family members, and the wider community can override an HIV-positive woman's decision not to have a child.¹⁸⁵
- In Botswana and South Africa, research has illustrated that gender power imbalances have an effect on women's ability to negotiate condom use with their partners.¹⁸⁶

170 USAID et al., 2005
 171 Mushi, Mpembeni & Jahn, 2007
 172 Varga & Brooks, 2008
 173 Skinner et al., 2003
 174 Thorsen et al., 2008
 175 Skinner et al., 2003

176 WHO, 2007
 177 Manzi et al., 2005
 178 Skinner et al., 2003
 179 Towle & Lende, 2008
 180 Zambia Central Board of Health, 2004
 181 Thorsen et al., 2008
 182 Towle & Lende, 2008
 183 Burke, 2004
 184 Thairu, Peltro, Rollins, Bland & Ntshangase, 2005
 185 London et al., 2008
 186 Langen, 2005



7.2 Community barriers

- If social support from the general community is perceived as low, this may have a negative impact on the up-take of PMTCT services and adherence to ARV treatment regimens.^{187,188}
- A women who fears a negative reaction from members of her community if she suddenly ceases exclusive breastfeeding at six months, may instead choose to carry on breastfeeding even if she is in the position to cease breastfeeding.¹⁸⁹
- Research in rural Burkina Faso demonstrated that women who perceived a positive attitude from their community were significantly more likely to participate in PMTCT counselling.¹⁹⁰

7.3 Social network barriers

7.3.1 Stigma

- Women may not access PMTCT services due to a fear of stigmatisation,¹⁹¹ as actively participating in a PMTCT programme or following specific recommendations can make public a woman's HIV status.^{192,193}
- In contexts where HIV is unjustly associated with promiscuous behaviour, as is the case in many sub-Saharan African countries, women may be reluctant to test because their partners may question their faithfulness and because they fear negative reactions from their partners or discrimination from the wider community.^{194,195,196,197}
- In the context of stigma, women have difficulty with disclosure of their HIV status.¹⁹⁸ Research in Soweto (South

Africa) found that stigma had not diminished and that women failed to disclose to their partners because they feared rejection from both their partner and their families.¹⁹⁹ Among 31 experiences of disclosure by females in Johannesburg (South Africa), 93.5% of the participants had voluntarily told their status to at least one person (usually a partner) within one week of receiving an HIV-positive test result. These primary disclosures were largely associated with positive responses and experiences. On the other hand, secondary disclosure, which was more often involuntary, was more likely to lead to rejection, stigma and withholding of financial support. Such research confirms the influence that socio-cultural norms have on disclosure experiences, sometimes creating a safe space for disclosure while at other times making disclosure a risky and difficult experience.²⁰⁰ Research in Botswana also indicated that women failed to disclose to their husbands because of stigma.²⁰¹

7.3.2 Gender-related issues and male partner/husband support

- Women in many African countries and other resource-poor settings have reported fears of discrimination, abandonment, rejection, divorce and or physical violence as reasons for not wanting to disclose their HIV-positive status to their male partner/husband.^{202,203,204,205,206,207} Research in South Africa found that women did not disclose their HIV status because of fear of abandonment and discrimination, even though the findings suggested that there are often fewer consequences than what was expected.²⁰⁸
- In many developing countries, women are often not in the position to make independent choices about their own health or that of their babies; therefore, it is often impossible for women to access PMTCT services without

187 Kagee, 2008

188 Perez et al., 2008

189 Thorsen et al., 2008

190 Sarker, Sanou, Snow, Ganame & Gondo, 2007

191 Skinner et al., 2003

192 Thorsen et al., 2008

193 Kebaabetswe, 2007

194 WHO & UNICEF, 2007

195 Thorsen et al., 2008

196 Tearfund, 2008

197 Dahl, Mellhammar, Bajunirwe & Bjorkman, 2008

198 Rigard, 2005

199 Garson, 2005

200 Varga, Sherman & Jones, 2006

201 Eide, Myhre, Lindbaek, Sundby, Arimi & Thior, 2006

202 WHO & UNICEF, 2007

203 Zambia Central Board of Health, 2004

204 Mlay, Lungina & Becker, 2008

205 Tonwe-Gold et al., 2009

206 Tearfund, 2008

207 King, Katuntu, Lifshay, Packel, Batamwita, Nakayiwa et al., 2008

208 Visser, Neufeld, De Villiers, Makin & Forsyth, 2008

disclosing their HIV status to their partner/husband.²⁰⁹

- In Nigeria, women have reported a number of practices from male partners that inhibit safe motherhood: physical violence, delaying access to obstetric care, encouraging heavy labour to induce birth, unwillingness to use family planning, withholding financial help, and blaming women for complications in pregnancy.²¹⁰
- Research in Tanzania showed that HIV-positive women whose partners attended VCT were three-times more likely to use Nevirapine prophylaxis and six-times more likely to adhere to the infant-feeding method they selected.²¹¹ These findings suggest that if a male does not know his HIV status or about PMTCT, his female partner is less likely to adhere to PMTCT strategies or to engage in PMTCT programmes.²¹²
- If a male partner disagrees with his female partner's decision to test for HIV then she may be unlikely to test.²¹³ The need to discuss whether to test or not with their partner is also a factor that leads to test refusal.²¹⁴
- Research showed that women who believed their partners/husbands would accompany them to an antenatal clinic and who expressed confidence in the fact that they would disclose their HIV status to their partners were significantly more likely to want to get tested. Research in Botswana found that a lack of male support prevented women from participating in PMTCT programmes.²¹⁵
- The majority of South African men seem to not involve themselves actively in reproductive healthcare and are not typically involved in consulting with their partners around family planning or antenatal issues.²¹⁶
- Research in South Africa indicated high levels of anger among women in response to men's perceived denial of males' responsibilities in PMTCT.²¹⁷
- Research in Uganda indicated that VCT up-take was relatively good among pregnant women, but not among their male partners/husbands.²¹⁸
- Childrearing in many African countries, such as Malawi, is viewed as being primarily the work of women, a view that is likely to prevent men from accessing PMTCT services or attending with their female partners, in turn inhibiting family-oriented models of PMTCT.^{219, 220}
- Research in Johannesburg (South Africa) indicated that male partners/husbands may not see the need for continual follow-up visits if their female partner has not disclosed to them.²²¹

7.4 Individual barriers

7.4.1 Lack of awareness and knowledge

- A lack of awareness and knowledge about HIV/AIDS and MTCT in the general population is an ongoing concern. Research in the Eastern Cape in South Africa indicated that knowledge levels about PMTCT are low not only among women and mothers, but also among mothers-in-law and male partners/husbands.²²²
- A national survey in South Africa in 2002 found that 46.8% of respondents demonstrated incorrect or uncertain knowledge about breastfeeding. It also found that respondents had either incorrect knowledge of, or were uncertain about, the causal relationship between HIV and AIDS.²²³
- A national survey in South Africa in 2005 found that 31.9% of 12–14-year-olds and 23.5% of individuals 50 years of age or older answered 'no' or 'do not know' when asked if HIV could be transmitted from mother to child. The survey also found that 18.7% of young people between the ages of 12 and 14 as well as 11.2% of adults over the age of 50 years did not understand the sexually transmitted nature of HIV.²²⁴
- Research in the Western Cape Province (South Africa) found that the participants had a high level of knowledge about HIV transmission and correctly knew that MTCT

209 Medley, Garcia-Moreno, Gill & Maman, 2004

210 Adeneye et al., 2006

211 Msuya, Mbizvo, Hussain, Uriyo, Sam & Stray-Petersen, 2008

212 Kebaabetswe, 2007

213 Sarker et al., 2007

214 Dahl et al., 2008

215 Baiden, Remes, Baiden, Williams, Hodgson, Boelaert et al., 2005

216 Mullick, Kunene & Wanjiru, 2005

217 Garson, 2005

218 Kizito, Woodburn, Kesande, Ameke, Nabulime, Mugwanga et al.,

2008

219 Tonwe-Gold, 2009

220 Tadesse, Muula & Misiri, 2004

221 Jones et al., 2005

222 Peltzer et al., 2007

223 Shisana & Simbayi, 2002

224 Shisana et al., 2005



was preventable. However, only 11% of these participants were able to correctly explain exclusive breastfeeding or mixed feeding.²²⁵

- A study across South Africa in 2005 found that 78.6% of males and 79% of females were aware of a place nearby to get tested for HIV. A lack of awareness of available PMTCT-related facilities and services will impact negatively on the uptake of PMTCT services.^{226, 227} The study also found, however, that 66% of adults and youths believed that they would not get infected; 69.7% of the respondents had not been tested, and the primary reason for this was the belief that they were either not HIV-positive or not at risk of infection.²²⁸
- South African research has reported gaps in mothers' knowledge about certain PMTCT strategies, such as exclusive breastfeeding. For example, the mothers' received limited advice on how to rapidly cease breastfeeding, showed little understanding about the rationale for rapid cessation and the dangers of continued breastfeeding, and they also demonstrated no awareness of the risks involved in replacement feeding.²²⁹ The literature is confusing in regard to breastfeeding. There is a considerable amount of literature arguing strongly for exclusive breastfeeding for six months, while other literature argues for the use of replacement feeding as this is less risky.²³⁰ The avoidance of topic of infant feeding in counselling sessions might reflect this confusion about breastfeeding.²³¹ Research in the Western Cape (South Africa) found that specific terms that should be used in counselling about infant feeding (including 'exclusive breastfeeding,' 'mixed feeding' and 'cup feeding') were not defined correctly by the majority of women. This suggests that not enough emphasis is placed on communicating the different infant-feeding options available to women.²³²
- Research in Burkina Faso found that a lack of understanding about the testing procedure has inhibited people from testing for HIV.²³³

- Research in Lesotho found that VCT is inhibited by the perceptions that individuals have about possible treatment options.²³⁴

7.4.2 Confusion about infant-feeding options

- Important and recurring findings from the literature concerned confusion about infant-feeding practices and the dilemmas facing HIV-positive mothers. Under the headings 'poor quality of counselling and information' and 'lack of awareness and knowledge' frequent reference has been made to uncertainty about the best infant-feeding option in relation to PMTCT.
- According to the South African policy on PMTCT, infant-feeding counselling should take into consideration the specific circumstances of each pregnant woman or mother so that an appropriate feeding choice is made. The AFASS (acceptability, feasibility, affordability, safety and sustainability) criteria should be used to help women decide on appropriate infant-feeding practices. The recommended feeding options for the first six-months are exclusive breastfeeding or exclusive formula feeding.²³⁵ In a study in Pretoria (South Africa), 74% of the women planned to formula feed despite the fact that only 30% had access to piped water; the median per capita income among the households was R320, and 76% of the women were unemployed. The large majority of the women in the study were influenced to use formula feed as a result of the counselling they received, suggesting that the AFASS criteria were not being used to assist women in the area to make appropriate infant-feeding choices.²³⁶
- In the case of pregnant women and mothers who choose to formula feed, the South African policy states that formula should be supplied for free to new mothers for a period of six months.²³⁷ The implication is that mothers (or their families) will have to purchase formula feed after the six-month allocation of free formula. In the case of breastfeeding, the policy states that HIV-negative babies should be exclusively breastfed for a period six months, followed by rapid cessation. If the infant subsequently tests HIV-negative and there is no food security, the pol-

225 Petrie et al., 2007

226 Gupta et al., 2007

227 Towle & Lende, 2008

228 Shisana et al., 2005

229 De Paoli et al., 2008

230 Petrie et al., 2007

231 Coovadia & Bland, 2007

232 Petrie et al., 2007

233 Sarker et al., 2007

234 Towle & Lende, 2008

235 Department of Health [South Africa], 2008b

236 Matji, Wittenberg, Makin, Jeffery, MacIntyre & Forsyth, 2008

237 Department of Health [South Africa], 2009a

icy states that exclusive breastfeeding should continue until the AFASS criteria are met or when the child reaches the age of 1 year.²³⁸ WHO also recommends cessation of breastfeeding after six months, or the continuation of breastfeeding in cases where replacement feeding is not feasible, for example because of financial constraints or lack of access to clean water.²³⁹ This approach has been supported by leading South African scientists.²⁴⁰

- The review of the literature highlights a level of confusion around infant feeding, and breastfeeding in particular. The general published discussion confirms that programme managers, counsellors, and pregnant women continue to be confused; thus, even at the level of scientific debate a certain level of polarisation continues to exist between those practitioners who support the avoidance of all breastfeeding among HIV-infected women, versus those who acknowledge the importance of the counselling approach to help women choose the feeding option most appropriate to them. The low levels of knowledge and awareness of infant-feeding options reported in the research confirms a need for clarity on the issue. In general, counsellors either avoid the topic in counselling sessions or else they push women in a particular direction; as a result women are given inadequate information to make an appropriate infant-feeding choice. There is clearly a need for scientists and practitioners to work together to develop clear guidelines and a consistent message based on scientific evidence that is contextualised within the cultural norm and local household settings.

7.4.3 PMTCT practices that are perceived of as discriminatory

- HIV testing is a practice that is generally associated with groups at higher risk of exposure to HIV. Active, 'opt-in' counselling and testing is likely to be avoided by pregnant women who may not identify with so-called high-risk groups or who may fear being associated with one of these groups.²⁴¹ Exclusive breastfeeding for the first six months of an infant's life may not be in line with general

breastfeeding practices nor with cultural norms; complying with this practice, therefore, often makes it impossible for women to hide their HIV status — a major concern for women living in a highly stigmatised context.²⁴²

- In contexts of economic constraints and food insecurity, receiving food parcels (for example) after PMTCT visits is likely to lead community members to assumptions about a woman's HIV status. In such contexts, women run the risk of being stigmatised and resented at the same time. The matter is complicated by attempts to hide these incentives in order to protect an HIV-positive woman's right to privacy. Such attempts on the part of programme providers may be misunderstood as colluding with the idea that being HIV-positive should be kept a secret.²⁴³ In a study in South Africa, high levels of stigma towards PL-WHA, and in particular mothers accessing free formula, forced mothers to hide their formula feed.²⁴⁴
- Home visits by PMTCT programmes are likely to expose a woman's HIV status, while she then risks becoming the object of gossip by surrounding community members.^{245,246}

7.4.4 Psychological barriers

- Fears of death, HIV testing, HIV-test results, and reactions to an HIV-positive status have been reported as psychological barriers to particular PMTCT services, such as VCT and disclosure of status.^{247, 248, 249, 250, 251, 252}
- Denial of one's HIV status and a sense of hopelessness are additional psychological barriers.²⁵³
- Shame has also been reported as a reason for not returning for follow-up visits.²⁵⁴

238 Department of Health [South Africa], 2008b
 239 De Paoli et al., 2008
 240 Coovadia & Bland, 2007
 241 Thorsen et al., 2008

242 Thorsen et al., 2008
 243 Thorsen et al., 2008
 244 Doherty et al., 2006
 245 Thorsen et al., 2008
 246 Eide et al., 2006
 247 Peltzer et al., 2007
 248 Burke, 2004
 249 Doherty et al., 2005
 250 Dahl et al., 2008
 251 King et al., 2008
 252 Kebaabetswe, 2007
 253 Tlebere et al., 2007
 254 Painter et al., 2004



8. Key participants to be reached through communication strategies

Overall, the published discussions about the barriers that impede the success of PMTCT programmes highlight that a number of key participants, rather than just HIV-positive pregnant women or mothers, should be the focus of PMTCT communication strategies. This is in line with the model of communication for social change, which stresses the role of dialogue and collective action to bring about a set of shared objectives. According to such an approach it is not appropriate to identify individuals to be targeted as though they are objects of change waiting to be fed information. Emphasis should rather be placed on developing relationships among relevant participants, who through cooperative action are able to bring about relevant change at both the individual and social level.²⁵⁵ The aim of communication should be to connect and mobilise people around a common cause.²⁵⁶

Within the context of PMTCT, the types of participants outlined in the following sections should be connected through participatory activities and dialogue in order to develop an integrated and consolidated approach to strengthening PMTCT programmes. A communication strategy that builds synergy and collaboration can position the PMTCT programme on a stronger structural footing.

8.1 Societal participants

8.1.1 Healthcare workers in rural and urban sites

Healthcare workers in rural and urban sites should include the full range of health workers identified across the literature discussed above, for example: HIV managers, programme directors, administrative staff, doctors, nurses, lay counsellors, full-time counsellors, supervisors and mentors.

Communication with these participants occurs at two interrelated levels. First, they are actively involved in communicating important PMTCT information to programme clients. The literature has shown how health workers' attitudes and interactions and levels of knowledge can become barriers that impede the success of PMTCT programmes. Second, these participants are themselves in need of up-to-

date information and ongoing training to ensure that they provide quality information and advice to their clients in a non-judgmental and non-discriminatory way.²⁵⁷

8.1.2 Representatives from various clinics, hospital sites and services

Discussions in the literature suggest that programme managers, clinic managers and healthcare workers need to consult with each other.

The literature discussed above shows that a lack of communication between different treatment sites and a lack of integration of various services (e.g., ANC and family planning with PMTCT) inhibit the success of PMTCT services. This indicates that there is an urgent need to bring together representatives from the different sites and service areas to participate in the development of communication strategies that will allow for consistent, integrated and comprehensive treatment of clients across sites and services.

8.1.3 Relevant government departments and policy-makers

The literature discussions of structural barriers indicate that various government departments need to engage with PMTCT strategies (e.g., the DoH and relevant sub-directorates within the HIV and AIDS Division, the Department of Communication, the Department of Social Development, and the Department of Transport).

Communication for social change recognises that there is an intimate link between individual and social change.²⁵⁸ The literature has shown that a number of contextual factors act as barriers to the implementation of PMTCT programmes. Poor healthcare infrastructure, staff shortages, a lack of telecommunications, poor access to government grants, and poor transport networks have all been identified as impeding the success of programmes. Linkages with government partners are therefore crucial in order to create channels for government to respond to these important social issues.²⁵⁹

255 Figueroa et al., 2006

256 Stackpool-Moore, 2006

257 PAHO/WHO, UNICEF, CENSIDA & Mexico, 2002

258 Vincent, 2006

259 Vincent, 2006

Communication with various government departments can contribute towards securing appropriate levels of government expenditure²⁶⁰ for PMTCT programmes. Furthermore, the DoH is responsible for the development of policies that guide the implementation of PMTCT programmes. Communication channels between the DoH and various health workers need to be encouraged and strengthened to ensure that they are informed about policy changes and relevant guidelines regarding PMTCT. Involving the government is an acknowledgment that communication is not just the task of outreach campaigns, but that communication has various social and political sources that should be integrated into a comprehensive strategy.²⁶¹

Research on family planning in South Africa also underscores the lack of guidelines for interdepartmental collaboration in terms of policy execution. For example, while condoms may be promoted by the DoH, condoms are not necessarily promoted by the Department of Education.²⁶²

8.2 Community participants

8.2.1 Community outreach workers

The literature reviewed identifies a number of individuals involved in community outreach that need to be engaged. Examples include: support-group leaders, mentors, and peer educators.

A perceived lack of community support, limited support from male partners/husbands, and high levels of stigmatisation are factors that have a negative impact on women's abilities to adhere to PMTCT components (such as exclusive breastfeeding for six months or attending follow-up sessions at clinics regularly). Community outreach workers, like support-group leaders, home-based mentors and peer educators, play a crucial role in communicating essential information within a context of care and support. These volunteers are in need of up-to-date information, resources and training²⁶³ to ensure that they are able to provide accurate information and psychosocial support.

8.2.2 Community organisations

The literature highlights the potential value of engaging with FBOs, NGOs, CBOs, women's organisations (including organisations focused on gender violence) and men's organisations.

CBOs are able to communicate important information through already established social networks and they may assist in overcoming some problems relating to inadequate transportation infrastructure²⁶⁴ by offering necessary services in decentralised ways. Despite these advantages CBOs can become a barrier to effective PMTCT strategies. For example, FBOs might not provide comprehensive family planning because of specific beliefs about appropriate sexual behaviour; youth may not be taught about contraceptives and unmarried serodiscordant couples may not be given safer-sex options that ensure the HIV-negative partner is not infected or options to avoid unintended pregnancies. So while community organisations can facilitate communication through already existing networks, they are also in need of up-to-date information and training to ensure that an ideological agenda is not put before a preventative agenda.²⁶⁵

8.3 Social networks

8.3.1 Influential community members

The literature discussed above draws attention to the importance of engaging key community members in PMTCT communication. Examples include: spiritual leaders, community leaders, respected elders and TBAs.

A number of cultural factors can impact negatively on PMTCT programmes, for instance: cultural beliefs about infant feeding and childbearing, the role of men in child-rearing, and taboos about talking about sexuality. These all have the potential to undermine the success of preventative measures. In addition, stigma continues to perpetuate fear and discrimination in contexts where HIV and AIDS is linked with groups at higher risk of exposure to HIV and higher-risk behaviours. Spiritual leaders, community lead-

260 Vincent, 2006

261 Shisana, Rehle, Simbayi, Zuma, Jooste, Pillay-Van Wyk et al., 2009

262 USAID et al., 2005

263 Vincent, 2006

264 Vincent, 2006

265 Vincent, 2006



ers, traditional leaders, traditional healers and TBAs are important sources of social communication.²⁶⁶ It is important to *partner* with these individuals — to equip them to actively communicate information that contributes to a supportive and enabling context for PMTCT and that works towards normalising the presence of HIV infections and AIDS illness. This supportive context will make it much easier to adhere to PMTCT practices that would otherwise be seen as alien to a particular community.²⁶⁷ The engagement of influential community members also ensures that communication occurs from within existing social networks, rather than being imposed from without,²⁶⁸ and that communication is sensitive to cultural beliefs. These community members will require information and supportive training to ensure that they relate accurate information and work towards developing social norms that will facilitate the PMTCT.

8.3.2 HIV-positive women's families

The literature discussed above emphasises the importance of engaging with the extended family, children, families-in-law, male partners/husbands and supportive friends of HIV-positive women who are pregnant or are mothers.

The literature reports that many women are reluctant to test for HIV or disclose their status because they fear rejection from their male partner/husband, their extended family and friends. The available research also shows that women are more likely to adhere to PMTCT strategies when they have the support of their male partners/husbands in particular. It is therefore crucial for PMTCT programmes to create communication networks throughout the family system rather than focusing their communication efforts on mothers alone. The family health model, which focuses on the entire family rather than just the mother, is one way in which these supportive links can be developed within family units.^{269,270,271} Communication between women and their male partners/husbands will contribute significantly to women's uptake of and adherence to PMTCT services

and interventions. Moreover, men, in particular, are in need of information about PMTCT interventions, like exclusive breastfeeding, to foster support for those PMTCT interventions that their female partners may have to adopt.

8.4 Individual participants

8.4.1 HIV-positive men and women (rural and urban)

The literature reveals the importance of a social network of support for HIV-infected women who may be pregnant or wanting to have a child; this highlights the importance of targeting both HIV-positive men as well as HIV-positive women who are pregnant or not pregnant.

HIV-positive women who are pregnant and women who are of childbearing age are often considered to be the 'primary targets' of PMTCT communication strategies. While a pregnant mother may transmit HIV to her child vertically if she does not adopt PMTCT practices, the literature as a whole suggests that she, alone, should not be the primary target of PMTCT information. HIV-positive mothers need to be supported to seek PMTCT services and to adopt PMTCT practices by creating a social network of support.²⁷² It is particularly important to involve the male partner/husband as he himself may be in need of HIV-related treatment and can be instrumental in encouraging his female partner to seek appropriate PMTCT services.²⁷³ This should extend in an integrated fashion to the broader family (see next section below).

8.4.2 HIV-negative women and men (rural and urban)

The literature discussed above highlights the importance of avoiding primary infection and unintended pregnancies amongst men and women of a reproductive age, male and female adolescents, and older men and women. Engaging with these groups also ensures a wider network of social support for HIV-positive women.

Primary prevention of HIV transmission is an impor-

266 Shisana et al., 2005

267 PAHO/WHO et al., 2002

268 Scalway, 2002

269 USAID (2005)

270 Horizons, 2009

271 Tonwe-Gold et al., 2009

272 Doherty et al., 2003

273 PEPFAR, 2004

tant component of PMTCT services and youth need to be addressed about HIV-prevention measures. Although HIV-negative women and men (both young and older) may not be seen as important targets for PMTCT information, they do in fact play a crucial role. One study found that there was a positive correlation between women who had been exposed to HIV education at school and their level of HIV knowledge when tested at an antenatal clinic. This shows that HIV-prevention education is important at the high school level²⁷⁴ and may increase the chances of a woman seeking out PMTCT services after she becomes pregnant. Other studies have also highlighted the importance of communicating MTCT and PMTCT information to youths at the level of the school.²⁷⁵ Some research has determined that youths can be important advocates for PMTCT in their family if they are knowledgeable about it.²⁷⁶ Other studies have shown the importance of educating the general population about PMTCT to harness greater support for mothers needing to adopt PMTCT practices. Thus, older women who may provide support for young mothers are also in need of information about PMTCT.^{277, 278} The literature proposes that people of all ages and from all localities need to be included in communication strategies since there tends to be poor programme reach among people ages 50 years and older, and also an urban bias, with poor reach in rural areas.²⁷⁹

274 Gupta et al., 2007

275 Shetty et al., 2008

276 UNICEF, 2002

277 Eide et al., 2006

278 Almroth, Arts, Quang, Hoa & Williams, 2008

279 Shisana et al., 2005



9. Key themes to be communicated in PMTCT messages

Embedded in the literature are a number of key themes that should be the focus of PMTCT messages. The importance of bringing people together to mobilise them in cooperative social action around the cause of PMTCT highlights that *all* the themes should, with minor exceptions, be communicated to *all* of the key participants meant to be reached.

The following sections outline the themes and messages that can be used in PMTCT communication strategies as they emerged from the literature.

9.1 Societal level

9.1.1 Caring, non-judgmental and non-discriminatory attitudes and actions^{280,281}

This message should be communicated widely but, more specifically, to healthcare workers who have in some contexts been reported to delay or even prevent HIV-positive clients from receiving necessary medical care. It has also been reported that in some contexts health workers, fearing HIV infection from treating an HIV-infected pregnant woman, will send the woman away from hospitals to deliver with a TBA.²⁸² It is important to communicate to healthcare workers the extent of the influence they have on the decisions that pregnant women and mothers make.²⁸³ Two-thirds of the research participants from an informal settlement in the Western Cape Province (South Africa) reported that a healthcare worker had advised them to formula feed; they had not received information about the different feeding options. Another study found that health workers influenced 80% of the women's infant-feeding choices. This suggests biased and subjective counselling, leaning in the direction of formula feeding.²⁸⁴

280 Skinner et al., 2003
281 Moore, 2003
282 Moore, 2003
283 Petrie et al., 2007
284 Petrie et al., 2007

9.1.2 Sexual and reproductive rights of HIV-positive women

The literature points out that the South African health system is one of the most coercive, where women are often forced into complying with medically accepted advice. It is essential that the general public and health workers are aware of the rights of HIV-positive pregnant women and HIV-positive women who are not pregnant, especially their sexual and reproductive rights.^{285,286,287,288,289,290,291,292,293}

9.1.3 The importance of family planning

It is important to discuss family-planning options with HIV-positive women and their male partners/husbands so as to avoid unintended pregnancies and to ensure that those who do want to have children are advised appropriately. Research confirms that some couples practicing high pregnancy-risk behaviours do not want a child²⁹⁴ and thus the importance of dual protection²⁹⁵ needs to be communicated both to avoid unintended pregnancy and HIV infection.²⁹⁶ Research confirms an unmet demand for family planning information^{297,298} and concludes that counsellors need to be trained to be sensitive to the needs of HIV-positive women and to respect a woman's right to make an informed decision about having a child or not and the desire to involve her partner in the decision-making process.²⁹⁹ Counsellors also need to be trained to make referrals to family-planning services and the counsellors should themselves be trained to inform women about family-planning options.³⁰⁰ There

285 Seidel, 2000
286 Cooper, 2008
287 Kgwete, 2008
288 Farlane, 2008
289 Scorgie & Crankshaw, 2008
290 Stevens, 2008
291 UNICEF, 2009
292 Pillsbury & Mayer, 2005
293 Eyakuze, Jones, Starrs & Sorokin, 2008
294 Nakayiwa et al., 2006
295 USAID, 2005
296 Mahendra, Mudoi, Oinam, Pakkela, Sarna, Panda et al., 2007
297 Rutenberg & Baek, 2004
298 McCarraher et al., 2008
299 Rutenberg & Baek, 2004
300 Mahendra et al., 2007

is also a need to provide the youth with friendly, comprehensive sexual and reproductive health education. Youths have a right to comprehensive and unbiased information, whether through education programmes concerned with sexuality and HIV or through family-planning or sexual health clinics.³⁰¹

9.1.4 Approaches to HIV-testing for pregnant mothers

The literature contains a number of debates about HIV-testing models meant to increase the uptake of PMTCT services. These various models need to be investigated and debated by relevant policy-makers and programme managers (with other relevant stakeholders) and the choice of HIV-testing model should be communicated unambiguously and consistently to healthcare workers. ‘Op-out’ models have been found to increase the uptake of services and therefore challenge the accepted practice of active voluntary ‘opt-in’ testing.³⁰² There are debates about the ethics and possibility of mandatory HIV testing in countries like Botswana,³⁰³ which might need to be addressed in relation to other countries.

9.1.5 The importance of a family-centred model for health³⁰⁴

The literature confirms that women are more likely to adhere to PMTCT practices in the context of familial support. The family health model for PMTCT should be communicated to all PMTCT sites. This model focuses not only on the mother, but also on other members of the family, including the male partner/husband. This message ensures greater male involvement in PMTCT.³⁰⁵

9.1.6 The importance of on-going support for mothers

Research has shown that mothers who are regularly informed about infant-feeding practices and supported in this regard tend to report higher levels of optimism than those who do not receive ongoing information and support. It was found that counsellors also reported higher levels of optimism as a result of providing regular information and support.³⁰⁶ Thus, programmes should importantly communicate the need for ongoing support from counsellors, health professionals, male partners/husbands and peer mentors/educators.

9.1.7 On-going training of healthcare workers to ensure quality services³⁰⁷

Up-to-date information has to be channelled to relevant participants. Ongoing, onsite training, mentoring and supervision are essential to ensure that information reaches relevant participants.³⁰⁸

9.1.8 Integrated ANC, PMTCT, postnatal care and family-planning services

The literature highlights the importance of integrating services that, in combination, can contribute to a decrease in MTCT. These include ANC, PMTCT and family planning. Notably, meeting the contraceptive needs of HIV-positive women requires that health workers and counsellors be trained to seek out and understand the fertility preferences of these women and to counsel them effectively on their reproductive choices. Informed-choice counselling is essential and HIV-positive women should not be coerced into particular reproductive decisions.³⁰⁹

9.1.9 Information on infant-feeding options and the need for counselling^{310,311}

The literature discussed in this review confirms the exis-

301 International HIV/AIDS Alliance, 2009
 302 Nuwagaba-Biribonwoha, Mayon-White, Okong & Carpenter, 2007; Creek, Ntuny, Seipone, Smith, Mogodi, Smit et al., 2009
 303 Clark, 2006
 304 Horizons, 2009
 305 Sonke Gender Justice Project, 2008

306 De Paoli et al., 2008
 307 Chopra et al., 2005
 308 Delvaux, Diby Konan, Ake-Tano, Gohou-Kouassi, Basso, Buve & Ronsmans, 2008
 309 WHO & UNICEF, 2007
 310 WHO & UNICEF, 2007
 311 UNICEF, 2009



tence of substantial confusion and pervasive low levels of knowledge about the significance of different infant-feeding options. In particular, knowledge levels concerning the importance of exclusive breastfeeding tend to be low. As a result, information imparted must be clear, unequivocal and up-to-date. The literature also confirms the need for 'objective' counselling that assesses the suitability of different feeding options for each mother and the importance of providing information that can empower mothers to make an informed choice about a feasible and sustainable infant-feeding option.³¹²

There is also a need for policies to be communicated to all relevant programme directors and healthcare workers.³¹³ Scientists and practitioners urgently need to engage with each other and devise appropriate recommendations and clear and consistent messages about infant-feeding options. A recent WHO technical consultation, for example, ended with the recommendation that there should be a revitalisation of breastfeeding promotion and support even in areas with high HIV prevalence.³¹⁴ Some researchers argue the importance of considering the appropriateness of formula feeding in contexts of poverty.³¹⁵ Clearly, all counselling on infant-feeding options should be contextualised to the particular socio-cultural circumstances of the individual mother.

9.1.10 Up-to-date information about programme implementation^{316,317}

Important data needs to be communicated to programme managers and other relevant participants. Relevant information includes, inter alia, PMTCT coverage per area, the mortality rate and causes of death in these areas, the number of people receiving antenatal and postnatal care, the number of people being tested for HIV and the number of extended family members being tested. The literature terms this 'information for action': because on the basis of this information the necessary steps can be taken to im-

prove programme success.³¹⁸ It is important to document HIV-free survival of children born to HIV-infected mothers and share this information with managers of PMTCT programmes and those involved in direct service delivery. The value and importance of facility-level data for programme management and for reinforcing health workers' practices are often neglected. This undermines data quality but also disconnects health workers from any sense of achievement and alignment with programme goals. Data function as feedback to staff concerning the outcome of their work and motivates them to take responsibility for the functioning of programmes.

9.1.11 Relevant policies and changes in policies

One barrier to effective implementation of PMTCT is the lack of communication of new policy decisions and changes in policy to relevant managers and healthcare workers. Meanwhile, it is important for the general public to be informed about current policy. Policy information is crucial for delivering effective and up-to-date PMTCT services and for promoting informed access to services.³¹⁹

9.1.12 Socio-economic and infrastructure constraints to PMTCT uptake³²⁰

It is important to communicate to the relevant participants that there are major socio-economic constraints that limit the ability of women to access and adhere to PMTCT services and practices like regular-follow up visits. The literature has shown that in certain contexts (particularly rural areas), poor telecommunications, poor transportation infrastructure, and people's inability to access grants can make it impossible for women to benefit from PMTCT services. Programme managers need to better understand the social circumstances of mothers.³²¹

³¹² Ogudele & Coulter, 2003

³¹³ Chopra et al., 2005

³¹⁴ Coutsooudis, Coovadia & Wilfret, 2008

³¹⁵ Coutsooudis et al., 2008

³¹⁶ Doherty et al., 2003

³¹⁷ Skinner et al., 2003

³¹⁸ Skinner et al., 2003

³¹⁹ UNICEF, 2009

³²⁰ Peltzer et al., 2007

³²¹ Okonkwo, Reich, Alabi, Umeike & Nachman, 2007

9.1.13 The importance of partnering with relevant NGOs^{322,323,324,325,326}

In areas where there are limited service sites NGOs can play a crucial role in communicating essential information about PMTCT and by offering certain PMTCT services (for example, counselling and testing).^{327,328} This requires increased collaboration and communication between government departments and NGOs. Opportunities exist for creative collaboration between the public health sector, individual facilities, local communities, and service users in order to overcome social and structural barriers to programme implementation and maintenance.

9.2 Community level

9.2.1 Beliefs about reproduction, childbearing and childrearing³²⁹

The literature shows that there are a number of cultural, traditional and religious beliefs that are likely to act as barriers to the uptake of PMTCT services. Men play a significant role in decision-making, and traditional infant-feeding and childbearing practices can run counter to the advice of PMTCT services. Consequently, information first needs to be communicated to clients in a way that is sensitive to cultural beliefs and practices³³⁰; second, these cultural practices should be engaged with and more widely debated within relevant spaces. For example, spiritual leaders and community leaders can usefully challenge the notion that only women are responsible for PMTCT. This suggestion is in line with the principles of communication for social change, which works towards taking debate and dialogue beyond behaviour to include social norms and culture, and so to create

a supportive environment for health-enabling decisions.³³¹

9.3 Social networks level

9.3.1 Importance of male support and engagement³³²

It is important to communicate that women would like their male partners/husbands to know the results of their HIV test. A study in Ghana indicated that 92.6% of women would prefer their male partner/husband to know the results of their HIV test.³³³ It is particularly important to communicate to women that despite fears of abandonment, violence or divorce, there may be far fewer adverse consequences than expected after disclosure to a male partner/husband, as some research has found.³³⁴ It is also important to inform health professionals that women are more likely to adhere to treatment plans if they have the support of their male partner/husband.³³⁵ Research in Kenya found that involving men in a pilot PMTCT programme led to a significant increase in the number of men who made use of the programme's VCT services.³³⁶ Research in KwaZulu-Natal Province (South Africa) found that men showed a desire to be involved in antenatal care, but did not feel skilled to do so.³³⁷ This shows the importance of engaging with men on the topic of their supportive roles. There should also be some discussion around the terminology of PMTCT; especially, emphasis should be placed on the idea that just because vertical transmission occurs between the mother and child, it should not be considered the sole responsibility of the mother to prevent HIV transmission. For example, India makes use of the term PPTCT (prevention of parent-to-child transmission of HIV) to emphasise the role of both parents rather than just mothers.³³⁸

322 Nair & Campbell, 2008
 323 Skinner et al., 2005
 324 Doherty et al., 2003
 325 WHO & UNICEF, 2007
 326 Mahendra et al., 2007
 327 Skinner et al., 2003
 328 IMAU & CDC [Uganda], 2003
 329 Skinner et al., 2005
 330 Kagee, 2008

331 Scalway, 2002
 332 Shetty et al., 2008
 333 Baiden et al., 2005
 334 Visser et al., 2008
 335 Msuya et al., 2008
 336 Peacock, Redpath, Weston, Evans, Daub & Greig, 2008
 337 Peacock et al., 2008
 338 Mahendra et al., 2007



9.3.2 Disclosure skills^{339,340}

The literature confirms that women who disclose their HIV-positive status to their husbands are far more likely to seek out PMTCT services and to adopt and adhere to PMTCT practices. Disclosure is also very important for serodiscordant couples so that decisions can be made about how to ensure that the uninfected partner does not become infected. Counselling should advise on the skills needed for disclosure.³⁴¹

9.3.3 Gender equity and women's rights^{342,343,344}

The literature describes a number of complex issues pertaining to gender which can impede the success of PMTCT programmes. Women are often dependent on their partners, and without their partner's permission they are not likely to test for HIV or access PMTCT services. Women in relationships characterised by unequal power relations are less likely to be able to negotiate the use of condoms.³⁴⁵ Messages about the rights of women and the importance of gender equity should be integrated into PMTCT communication strategies. This is particularly important in contexts with a high level of violence against women.

9.4 Individual level

9.4.1 Key components for HIV prevention at an individual level³⁴⁶

It is important to communicate the importance of early ANC visits, the different treatment options for PMTCT, the obstetric practices that can reduce the chances of MTCT, and the importance of enlisting a skilled TBA if a woman chooses to have her child outside the formal healthcare

sector. It is also important to communicate about birthing preparedness to ensure that appropriate actions are taken for PMTCT. The importance of a continuum of care and ongoing follow-up visits for mothers and infants needs to be communicated³⁴⁷ as well as the need for follow-up visits with both the mother and the father of a newborn. Messages about OB practices, for example, should not be channelled only towards mothers-to-be, but to families and the public to create wider social awareness about PMTCT.³⁴⁸

9.4.2 Accurate facts about HIV/AIDS, MTCT and PMTCT^{349,350}

The available statistics prove that although many people have some general knowledge about HIV and AIDS they tend to have very limited knowledge about MTCT and PMTCT, which can limit the success of PMTCT programmes.^{351,352} It is essential that all relevant participants are equipped with this information and that the general awareness of HIV/AIDS and PMTCT is increased widely.³⁵³ The review of the literature so far has identified the following areas around which information needs to be specifically communicated:

- MTCT transmission routes;
- Infant-feeding options, including exclusive breastfeeding, exclusive formula feeding and mixed feeding;
- Early cessation of breastfeeding;
- Formula feeding and related terminology;
- The causal link between HIV and AIDS;
- The sexually transmitted nature of HIV;
- The risks of infection;
- The various PMTCT strategies;
- The availability and location of PMTCT services;
- VCT and the HIV-testing procedure;
- HIV-related treatment options.

339 WHO & UNICEF, 2007

340 WHO & UNICEF, 2007

341 Tonwe-Gold et al., 2009

342 Sonke Gender Justice Project, 2008

343 Eide et al., 2006

344 Vincent, 2006

345 Langen, 2005

346 Moore, 2003

347 Mahendra et al., 2007

348 Moore, 2003

349 Skinner et al., 2003

350 WHO & UNICEF, 2007

351 Eyakuze et al., 2008

352 Mushi et al., 2007

353 Kasenga, Byass, Emmelin & Hurtig, 2009

9.4.3 Importance of knowing your HIV status

Knowing one's HIV status is particularly important for the primary prevention of opportunistic infections and new HIV infections, but also essential for pregnant women or couples wanting to have a baby.³⁵⁴ The benefits of HIV testing,³⁵⁵ information about the testing procedure, and the location of testing services all need to be communicated to prospective parents.³⁵⁶ Research has shown that women who knew their HIV status were more likely to change their higher-risk behaviours and were likely to change these behaviours out of concern for infant health and transmitting the virus to others.³⁵⁷ But there is also research evidence showing that male participation in VCT may be low for partners of both HIV-positive and HIV-negative women: this highlights the need for more VCT communication interventions that target males.³⁵⁸ This brings to light that alongside communication about the importance of testing, the specific benefits of HIV testing for the wellbeing of one's infant should be communicated.

354 Moore, 2003

355 Shankar, Pisal, Patil, Joshi, Suryavananshi, Shroti et al., 2003

356 Burke, 2004

357 Tavengwa, Piwoz, Iliff, Moulton, Zunguza, Nathoo et al., 2007

358 Msuya et al., 2008



10. Good practices

The following broad contextual factors have been identified in the field of HIV/AIDS communication (including PMTCT communication approaches, specifically) as contributing towards successfully planning and implementing HIV/AIDS communication campaigns^{359,360}:

- A relatively free and open media;
- An active civil society;
- An engaged political leadership;
- A critical analysis of the HIV epidemic, moving beyond sexual behaviour to explore relevant contextual factors (e.g., gender issues, discrimination and poverty) that contribute to the spread of HIV;
- Open dialogue through personal communication networks;
- Harnessing local expertise;
- A multisectoral response to HIV and AIDS.

In November 2001, the VIII International Communication for Development Roundtable, held in Managua, Nicaragua came to the disturbing conclusion that despite evidence that highlights the effectiveness of responses that prioritise collaborative and community participation, communication responses to HIV and AIDS are too often driven by donor demands, tend to be short-term, narrowly focused and largely uncoordinated. Participants at the roundtable were concerned with the fact that externally conceived and vertically imposed processes characterise communication responses to the HIV epidemic.³⁶¹

A 10-year (1998–2007) systematic review of HIV/AIDS mass communication campaigns confirms that there is still a strong preference for communication campaigns based on theories of behaviour change. The review reports on a shift from raising awareness to changing behaviour, but makes no comment on the need for campaigns to focus on social transformation to create supportive contexts for behaviour change.³⁶² The systematic review also gives the impression that publications based on social change and participatory

approaches tend to not meet the inclusion criteria for such reviews by virtue of their design and/or analysis. For example, a recent review of community-based initiatives directed at youth found that only eight of 96 studies fulfilled three or more of the inclusion criteria.³⁶³ We argue that the integrative approaches to communication should be as rigorously evaluated as the less multi-dimensional behaviour-change approaches, as it is the rigor of the evaluation methodologies — rather than the qualities of the programme evaluated — that excludes them from consideration in meta-analyses. The roundtable concluded that there is a need to work within the UNAIDS framework that identifies five contextual domains on which communication strategies should focus³⁶⁴:

1. Government policy
2. Socio-economic status
3. Culture
4. Gender relations
5. Spirituality.

The roundtable further recognised the value of the communication-for-social-change approach; in conclusion the participants made the following two recommendations regarding communication in the context of HIV and AIDS³⁶⁵:

1. Challenge donors and international organisations to recognise the importance of social-change communication over and above behaviour-change strategies.
2. Community ownership, participation, and debate should ensure that local community agendas are placed above those of donors and international organisations.

A 2002 UNICEF analysis identified the following aspects of better practices in PMTCT communication strategies in Zambia, Rwanda, Thailand, India, Nigeria and South Africa. The document emphasised that due to a number of barriers there was no one country that met all the criteria for better practice in PMTCT communication; but by identifying the aspects of better practice an overall better-practice strategy can be developed. The following aspects of better practice were identified³⁶⁶:

359 Scalway, 2002

360 Vincent, 2006

361 Scalway, 2002

362 Noar, Palmgreen, Chabot, Dobransky & Zimmerman, 2009

363 Kim & Free, 2008

364 Scalway, 2002

365 Scalway, 2002

366 UNICEF, 2002

- **Community-based PMTCT research:** This entails identifying (through community-based research) the potential barriers to PMTCT services and addressing them before offering PMTCT services. This can be accomplished using innovative research methods, such as narrative workshops, to identify the contextual factors that either promote or inhibit the uptake of PMTCT services. In this way, research findings are used as the foundation on which communication strategies are designed.
 - **Community participation:** The development of communication strategies should include high levels of community participation and a variety of stakeholders (e.g., traditional healers, home-based caregivers, lay counsellors, care and support groups, men's groups, women's groups, and youth groups).
 - **Team counselling and a caring atmosphere:** A compassionate and welcoming environment and good-quality individual and group counselling (maintained through a process of peer review, ongoing training, management and supervision) are needed to enhance people's experiences of and desire to access PMTCT services.
 - **Counselling training:** Ongoing training will improve counsellors' confidence and job satisfaction, which in turn increases interest and uptake in PMTCT programmes.
 - **Community preparedness:** Community preparedness activities are included to introduce and sensitise communities to the benefits of various PMTCT services.
 - **Youth advisory groups:** Youth advisory groups ensure that PMTCT communication interventions are interesting to the youth and appropriately focused on them. Some areas have made use of youth camps to ensure that at least one youth per household is knowledgeable about HIV/AIDS and PMTCT. These youths can act as PMTCT advocates within their families.
 - **Consistent PMTCT messages:** This highlights the importance of evidence-based, and clear and consistent messages about various aspects of PMTCT, including infant-feeding options.
 - **Improving the attitudes of health workers:** Introspective sessions are built into some training programmes to encourage health workers to explore how they feel about treating HIV-positive clients and why they feel this way.
- This contributes towards creating a less stigmatising and discriminatory environment for clients.
- **Community dialogue:** Community partnerships foster dialogue and collaboration within the community. Community members may identify positive aspects of their community and how existing social problems can be successfully dealt with. Thus, the community receives accurate information about HIV/AIDS and PMTCT and is mobilised to create more caring and supportive environments.
 - **Overall planning for PMTCT communication:** Community-based qualitative and quantitative research is used for developing tailored PMTCT communication strategies.
 - **Communication teams:** A multi-sectored team approach is used to ensure that communication activities are appropriately implemented and in a timely manner. These teams include a number of stakeholders, including members from various community organisations, PLWHA, religious leaders, local opinion leaders and members of the private sector.
 - **Integration of services:** A key global lesson learnt is the importance of integrating PMTCT into routine ANC service delivery.



11. Strategies for strengthening PMTCT

11.1 Societal level

11.1.1 Media communication strategies

While a large portion of this review has dealt with interpersonal and community communication, less has been said about the role that media can play in promoting PMTCT. Most South Africans access some form of mass media a few days or more per week. National research in South Africa in 2005 found that exposure to radio is the highest, followed by television, newspapers and magazines.³⁶⁷ Further research confirmed that television reaches the greatest number of South Africans, followed by national radio, local radio, community radio and local community events. The research explored the impact of 19 HIV/AIDS communication programmes in South Africa: the reach ranged from 4% for participation in the government's Khomanani campaign and The Journey community radio drama, to a high of 65% for the television drama Soul City.³⁶⁸ The national research project was recently repeated and found that the four flagship HIV/AIDS communication campaigns in South Africa — Khomanani, Soul City, Soul Buddyz and loveLife — had all increased their reach, with the highest being Soul City at 44.1%, followed by loveLife at 42.5%. This upward trend is particularly noticeable among the youth, as 90% were already reached by at least one programme.³⁶⁹ Mass media is therefore proving to be an important vehicle through which important PMTCT information can be channelled. However, large differences in patterns of HIV prevalence, risk behaviours, and the reach of communication programmes in different provinces calls for a carefully targeted and diversified approach to HIV, and by association, PMTCT communication.³⁷⁰

A qualitative analysis of HIV/AIDS-related media coverage shows that newspapers in South Africa can be used more effectively to communicate information about HIV/AIDS related issues. Newspapers tend to deliver responses that are largely based on occurrence of events, and the sources of these articles tend to be politicians, bureaucrats

and civil society leaders. There is less emphasis placed on finding local stories or linking national, provincial and local issues, while rural areas commonly receive less coverage. Only 38% of the articles provided some factual knowledge about HIV or AIDS.³⁷¹ Newspapers can clearly play a much more constructive role in communicating important information about PMTCT and the experiences of PLWHA, which will serve to increase awareness and help decrease stigma and discrimination.

There is reason to be cautious when using mass media to disseminate information as it also has the potential to reproduce problematic understandings or representations unless the information or messages are carefully and critically thought through. For example, a discourse analysis of South African newspaper articles writing about HIV and AIDS found that black African parents and families were problematically portrayed as failing their moral duties towards children, while middle-class individuals were portrayed as going beyond their moral duty in the context of HIV and AIDS.³⁷² Other research found that the media can be responsible for contributing towards stigma, by, for example, making a link between formula feed and being HIV-positive. Mass media needs to be actively involved in challenging potentially harmful norms rather than reproducing them. For instance, there has been a call for the news media to ensure that HIV-related information and education is more inclusive of and aimed at young men, and that it should aim at disrupting various elements of masculinity which could increase young men's risk of HIV infection.³⁷³

Research in South Africa has confirmed that national-level mass media HIV/AIDS communication programmes have an indirect influence on individuals' HIV status through their effect on several HIV-prevention behaviours. This finding challenges the commonly held belief that HIV-prevention campaigns are not working in South Africa.³⁷⁴ There is plainly a need to look into the possibility of using mass media communication to support interpersonal and community PMTCT communication strategies.

367 Shisana et al., 2005
 368 Kincaid, Parker, Schierhout, Connolly & Pham, 2008
 369 Shisana et al., 2009
 370 Shisana et al., 2009

371 Spurr, 2005
 372 Meintjies & Bray, 2005
 373 Scalway, 2001
 374 Kincaid & Parker, 2008

11.1.2 Recommendations

Stigma reduction: implications for communication strategies

The literature stresses that stigma undermines the effectiveness of PMTCT programmes. The literature also disturbingly points out that few campaigns that have attempted to address stigma have been successful.³⁷⁵ Despite this finding, it is important to continue to work towards breaking the silence around HIV and AIDS. To do this effectively we must necessarily broaden discussions around HIV and AIDS. Communication needs to move beyond the personal sphere into the interpersonal and public arena to assist in breaking down stigma and discrimination.³⁷⁶ The relevance of this statement is confirmed by local research that found that although many South Africans are reached by national HIV/AIDS campaigns, the campaigns tend to have poor reach among those aged 50 or older, and they are primarily run in urban areas. Many South Africans have reported that their information more often comes from interpersonal communication and community activities rather than formal campaigns. It was also found that family and friends were frequently sources of information. There is clearly a need to move HIV/AIDS communication into the public arena in South Africa in order to increase awareness of HIV and AIDS and PMTCT and thereby reduce stigma.³⁷⁷

Addressing gender equality

Gender relations are difficult to address through interventions and can only be adequately addressed through a combination of communication processes and simultaneous advocacy and social mobilisation.³⁷⁸ The literature brings to light that unless gender equality is integrated into PMTCT programme design, issues such as gender inequity will continue to undermine the effectiveness of the programmes.

The following suggestions have been made concerning how to address gender equality through communication and social mobilisation within the context of HIV/AIDS and PMTCT:

- Work at creating a supportive social environment for the rights of women and girls, which is essential for improved PMTCT success. This can be achieved by ensuring that females stay in school and receive a quality education, that women are protected from violence and other forms of abuse, that women are not exploited or discriminated against on the basis of their gender, and by involving young men and male partners/husbands in childcare as well as in helping to ensure use of PMTCT.³⁷⁹
- Make use of existing programmes and interventions that inform men and women, young and older, about gender-related issues, including rights. For example, several manuals have been developed which can be adapted for the South African context. Two potentially useful manuals are 'Working with young women: empowerment, rights and health'³⁸⁰ and 'Young men and HIV prevention: a toolkit for prevention.'³⁸¹

Improving health systems and integrating services

The literature has highlighted a number of systemic factors that are likely to impede the effective delivery of PMTCT programmes. Integrating health services increases opportunities to communicate important information about HIV/AIDS and PMTCT to a larger number of people accessing health services. The integration of services is also likely to encourage participation as routine links to a number of integrated services is less stigmatising than being referred to one specific service that is clearly HIV/AIDS-related.³⁸² An overburdened healthcare system is also likely to impact on the quality and availability of services. The literature points out that a lack of staff and insufficient treatment sites has prevented people from accessing PMTCT services. Unless these issues are dealt with, the effectiveness of PMTCT services is likely to be undermined.

The following recommendations have emerged largely from the published literature that identifies and explores barriers to PMTCT programmes:

- Develop a network of trained lay counsellors to increase the uptake of services like VCT that are often compromised by a shortage of staff.³⁸³

375 Vincent, 2006
 376 Vincent, 2006
 377 Shisana et al., 2005
 378 Vincent, 2006

379 UNICEF, 2009
 380 Promundo Salud y Genero, ECOS, Instituto PAPAI & World Education (no date)
 381 Ricardo, Barker, Nascimento & Segundo, 2008
 382 Vincent, 2006
 383 McKee, Bertrand & Becker-Bento, 2004



- Improve clinic infrastructure (confidential spaces), working conditions, the provision of sufficient equipment, and the involvement of staff in decision-making, which is crucial to staff retention and efficient programme implementation.³⁸⁴
- Streamline communication channels to ensure that all policy decisions and clinical protocols are conveyed in a timely manner to all relevant health professionals.^{385,386}
- A decentralised approach is important to decrease the number of women who are lost to follow-up due to the fact that they cannot reach treatment sites.³⁸⁷
- Provide 4x4 vehicles, off-road motorcycles and cell phones in areas with poor transportation infrastructure and telecommunications to improve PMTCT implementation in certain, largely rural, contexts.³⁸⁸
- Develop a continuum of care within the healthcare system³⁸⁹ and strengthen referral systems within healthcare sites and between different services.³⁹⁰
- Explore 'opt-out' counselling in antenatal clinics to increase access to and use of PMTCT services.³⁹¹
- Develop male-friendly counselling outside of antenatal clinics. Although PMTCT programmes are important entry points for male involvement in PMTCT, the traditional clinic-based approach to harnessing their support and engagement has reached relatively few men.³⁹²
- Integrate PMTCT, VCT, ANC and family-planning services. Research showed that the integration of family-planning and VCT services does not necessarily compromise the quality of the services, and that there were financial savings.³⁹³ Integrated interventions also serve to reduce stigma and discrimination, since a person is not expected to move to different sites or labelled rooms, and this also promotes the right to services and increases access to services.³⁹⁴
- Offer training on the integration of family planning and HIV/AIDS-related issues.³⁹⁵
- Increase the availability of male-friendly health clinics. Clinics that extend opening times to accommodate men who work, and clinics that employ male staff, have shown success in increasing the number of men who access VCT.³⁹⁶

HIV and having children

A recent HSRC report points to a trend wherein young people who have thus far managed to avoid HIV infection are approaching the 25–29 age cohort in which young women's risk of acquiring HIV infection rises to one in three, and young men's to one in four. The report recommends that HIV-safe-ways of conceiving need to be developed and communicated especially to young adults.³⁹⁷ This corroborates recurrent recommendations in the literature stating that the fertility desires and contraceptive practices of HIV-positive and HIV-negative men and women need further research.

The needs of men and women for family planning and PMTCT also merit additional research (see section 12). Another suggestion repeatedly mentioned is that more research is needed on the attitudes of HIV-positive and HIV-negative men, women, and healthcare workers towards HIV-positive mothers who choose to have children.

11.2 Community level

11.2.1 Media communication strategies

In line with the principles of communication for social change, it is essential to ensure that communication campaigns involve existing community networks and relevant stakeholders. Community involvement ensures internally driven change rather than change that is imposed from the outside (for example, by funders).³⁹⁸ Community dialogue is also a critical element of communication for social change as it constitutes effective dialogue said to lead to collective

384 Delvaux et al., 2008

385 WHO & UNICEF, 2007

386 Doherty et al., 2003

387 Perez et al., 2004

388 Skinner et al., 2003

389 UNICEF, 2009

390 Stevens, 2008

391 Spensley, Sripipatana, Turner, Hoblitzelle, Robinson & Wilfret, 1999

392 Msuya et al., 2008

393 USAID, FHI & DoH [South Africa], 2005

394 International HIV/AIDS Alliance, 2009

395 USAID, 2005

396 Sonke Gender Justice Project, 2008

397 Shisana et al., 2009

398 Program for Appropriate Technology in Health (PATH), 2006

action and relevant social change.³⁹⁹

Strategies like discussion forums, community discussions, radio listening clubs and awareness training have helped reduce stigma by promoting discussion and awareness of the realities facing HIV-positive people.⁴⁰⁰ PMTCT programmes have identified media briefs and working with local radio stations and television shows as part of their PMTCT communication strategies.^{401, 402} There are a number of guidelines available on how to plan and deliver media broadcasts. One such guide, ‘Soap operas for social change to prevent HIV/AIDS: A training guide for journalists,’ provides guidelines on developing edutainment dramas for HIV prevention among young women and girls.⁴⁰³

As pointed out, newspapers can undoubtedly play a more constructive role in communicating important information about PMTCT and the experiences of PLWHA; this would serve to increase awareness and help to decrease stigma and discrimination. Community newspapers are very useful communication tools — not only as a source of information, but also as a mirror reflecting community life and values.

An innovative intervention called ‘Women Connect!’ is an example of how developing skills in using media and information communication technology can lead to increased access to health-rights information for women, both young and older. This programme has resulted in a number of innovative media projects, including radio broadcasts on family planning, media campaigns on avoiding teenage pregnancy, newsletters and training manuals.⁴⁰⁴

Some may argue that the use of media and advanced technology may not be feasible in a resource-constrained setting. There is, however, evidence showing that carefully planned, low-cost broadcasts can be effectively used in resource-constrained setting to reach effectively people with HIV/AIDS-related messages.⁴⁰⁵

11.2.2 Recommendations

The following recommendations regarding community-level communication strategies have emerged largely from the literature that discusses existing barriers to PMTCT implementation:

- Adopt successful programmes like the Baby Friendly Hospital and certain community initiatives to increase understanding of the importance of exclusive breastfeeding.⁴⁰⁶
- Select and train appropriate peer counsellors. Peer counsellors can contribute significantly to improved breastfeeding strategies (for example, adherence to exclusive breastfeeding) by providing ongoing support to mothers and providing counselling to extended family members.^{407, 408} Peer education in antenatal clinics has, for example, been found to be feasible, acceptable and sustainable.⁴⁰⁹

Develop mother-to-mother support programmes. Research has shown the effectiveness of community-based interventions like the mother-to-mother (m2m) programme,⁴¹⁰ where HIV-positive mothers are used as mentors to support similar women. This programme has had a substantial impact on PMTCT, with reports of increased interaction between mothers and a reduction in the number of children born HIV-positive. It has also led to an increase in the number of women who disclosed to their partners and family.⁴¹¹ The m2m programme is based on two main assumptions: first, that peer support is an effective model of communication and empowerment, and, second, that mothers themselves are the best vehicles to provide support to other mothers. Mentors engage in various activities, including providing health talks, individual and group education, and regular support meetings. Mentors are also involved in community outreach programmes that assist mothers in decisions about disclosure and treatment (there was a significant increase in disclosure, treatment and the number of women reporting an exclusive-feeding practice).

399 Figueroa et al., 2002

400 Vincent, 2006

401 Zambia Central Board of Health, 2004

402 IMAU & CDC [Uganda], 2003

403 Barker & Sabido, 2005

404 Pillsbury & Mayer, 2005

405 Myhre & Flora, 2000

406 Coovadia & Bland, 2007

407 Haider, Kabir & Huttly, 2000

408 Khan, 2007a

409 Shetty et al., 2008

410 Scorgie & Crankshaw, 2008

411 Mothers2Mothers, 2007



The general wellbeing of women who participated was shown to be significantly greater than those who did not.⁴¹² A (pre-existing) programme, similar to m2m, called ‘mothers-to-mothers-to-be’ (m2m2b) involved training HIV-positive mothers who had recently delivered to share their personal experience to encourage adherence to treatment and infant-feeding choices, and to encourage uptake of PMTCT services.⁴¹³ The m2m2b programme has been implemented in five provinces in South Africa and has been adopted as part of the national HIV/AIDS strategic plan.

- Develop interventions aimed at increasing men’s awareness of PMTCT. Research found that a community intervention that included inviting men to the local clinic for VCT, aiming education at men, and providing support groups for women resulted in increases in spousal communication about PMTCT, the number of male partners who attended VCT, and the disclosure of HIV-test results by both partners.⁴¹⁴
- Conduct community preparedness activities with male leaders and opinion leaders. Research has found that these preparedness activities lead to an increase in the uptake of testing by men (when the service was made available).⁴¹⁵
- Encourage key community members (e.g., community leaders and spiritual leaders) to communicate information about PMTCT and encourage support of PMTCT.⁴¹⁶
- Develop PMTCT support groups to assist newly diagnosed mothers, and on an ongoing basis.⁴¹⁷
- Develop male-sensitive support groups where men can get support with dealing with issues such as disclosure.⁴¹⁸
- Intensify community awareness campaigns about HIV/AIDS, PMTCT and related services, which has been found to increase acceptance of HIV testing and counselling.⁴¹⁹ These awareness campaigns should work towards normalising HIV testing and living with HIV in the wider community; this in turn will help reduce the social stigma that threatens to undermine the success of preventative programmes.⁴²⁰

- Use cultural and community events to communicate HIV/AIDS and PMTCT information to the wider community (e.g., public meetings, seminars, prayer groups and wedding celebrations).⁴²¹
- Use recreational spaces and events to communicate HIV/AIDS and PMTCT information to the wider community (e.g., drama, sporting events, market days, existing television and radio shows, and home visits).⁴²² Interactive theatre is an example of using drama to encourage community dialogue about HIV/AIDS, as it encourages audience participation and discussion.⁴²³
- Use the ministerial izimbizo⁴²⁴ conducted by the DoH to raise concerns at the highest political levels, particularly in regard to PMTCT implementation. This is an especially important forum for community mobilisation and advocacy.
- Develop community activities that increase understanding of and can help change the harmful social, cultural and gendered norms that sometimes obstruct PMTCT programmes.⁴²⁵
- Develop partnerships with NGOs and CBOs, which can, through their existing networks, alleviate some of the burden on the healthcare system^{426, 427} and offer services in under-resourced contexts.⁴²⁸
- Develop community capacity by educating various community stakeholders in PMTCT (e.g. community leaders, men’s and women’s groups, spiritual leaders, youth groups, traditional healers and TBAs).⁴²⁹
- Select and train appropriate HIV-positive people as network support agents (NSA). Agents deployed in health facilities have been found to increase links between com-

412 Khan, 2007b

413 Moore, 2003

414 Moore, 2003

415 Sonke Gender Justice Project, 2008

416 IMAU & CDC [Uganda], 2003

417 Moore, 2003

418 Sonke Gender Justice Project, 2008

419 Perez et al., 2004

420 Thorsen et al., 2008

421 IMAU & CDC [Uganda], 2003

422 IMAU & CDC [Uganda], 2003

423 Program for Appropriate Technology in Health (PATH), 2006

424 Department of Health [South Africa], 2009a

425 International HIV/AIDS Alliance, 2009

426 Msuya et al., 2008

427 Nair & Campbell, 2008

428 Skinner et al., 2003

429 Skinner et al., 2003

munities, support groups, and other PMTCT-related services at the levels of healthcare and the community. These agents may meet with support groups and people in their homes where they provide counselling and information and make appropriate referrals to services, including VCT, PMTCT and family planning. They can also be involved in facilitating general community awareness and advocating for accessible and quality services.⁴³⁰

11.3 Social network level

11.3.1 Communication strategies

Research in South Africa shows that national-level, mass media HIV/AIDS communication programmes can have an indirect influence on individuals' HIV status through their effect on several HIV-prevention behaviours. This finding challenges the commonly held belief that HIV-prevention campaigns are not working in South Africa.⁴³¹ We should explore the possibility of using mass media communication to support PMTCT interpersonal and community communication strategies. Radio programmes have, for example, been shown to be effective in changing attitudes towards family planning and increasing spousal communication about family planning.⁴³²

There is a need to network and dialogue with community elders and leaders in order for them to understand the existing structures and social networks that can support the implementation of PMTCT programmes.⁴³³

11.3.2 Recommendations

- Invest in the 'mother-to-mother plus programme,' or an adaptation thereof, which is essentially a family-focused health model that has been successful in enrolling HIV-positive women, partners and children in HIV/AIDS-related and PMTCT-related activities. A multi-disciplinary team, including physicians, nurses, midwives, counsellors, outreach workers, pharmacy personnel, can lead to

remarkable levels of client retention.⁴³⁴ This is also an innovative way of involving male partners in the PMTCT process.⁴³⁵

- Ensure that family planning services also address gender issues and works at increasing males' involvement. One strategy is to renew the focus on couples counselling, as shown in research from South Africa.⁴³⁶
- Make use of appropriate communication approaches that encourage men and women to talk about issues like sexuality and gender norms and practices that are potentially harmful to women.⁴³⁷
- Encourage young men and male partners/husbands to take part in child care and also in ensuring PMTCT.⁴³⁸

11.4 Individual level

11.4.1 Communication strategies

The Baby Friendly Hospital is a very successful programme that contributes to an increase in understanding the importance of exclusive breastfeeding.⁴³⁹

As pointed out in the section on the social network level, above, there is plainly a need to investigate the possibility of using mass media communication to support interpersonal and community PMTCT communication strategies. Interpersonal communication within this context largely refers to communication via one-on-one interactions between clients and healthcare professionals during PMTCT consultations and counselling. Research has shown that poor-quality counselling and the poor attitudes of counsellors and healthcare providers can hinder PMTCT implementation.

PMTCT counselling can be seen as a particularly complex form of counselling as it often involves sensitive issues like parenthood, the possible death of an infant, difficult decisions about whether or not to conceive, the negotiation of normative behaviours (including infant feeding and childbearing, negotiating safer sex and relationship dynam-

430 International HIV/AIDS Alliance, 2009

431 Kincaid & Parker, 2008

432 Boulay, Storey & Sood, 2002

433 Skinner et al., 2003

434 Tonwe-Gold et al., 2009

435 USAID, 2005

436 USAID et al., 2005

437 Vincent, 2006

438 UNICEF, 2009

439 Coovadia & Bland, 2007



ics⁴⁴⁰), and coping with an infant who tests HIV-positive postnatally. VCT, for example, is considered the cornerstone of most PMTCT services because it is through this process that women find out their HIV status and are encouraged to enrol in a PMTCT programme if they test positive. Giving advice and counselling as part of PMTCT services and decision-making requires specific training in both communication skills and in the content that will be communicated.

11.4.2 Recommendations

The following specific recommendations to improve the quality of counselling and interactions have appeared primarily in the published research concerning barriers to PMTCT:

- Key selection criteria should be used to select appropriate people for PMTCT counselling.^{441, 442}
- Build on existing resources to develop a standardised counselling training programme⁴⁴³ that can be adapted for different health professionals, in line with their specific job descriptions, and most importantly to ensure that all partners are using the same training programmes.
- Train counsellors and other relevant health workers to communicate information in a non-prescriptive and non-coercive way. Counsellors should be taught to encourage dialogue and debate about relevant issues (including socio-cultural and psychosocial dimensions) and should encourage their clients to ask questions as well as help empower them to make informed choices rather than enforced decisions.⁴⁴⁴
- Counselling skills should be integrated into the entire health team, and all health professionals could be encouraged to be trained in PMTCT by making it a condition for re-registration with their respective Health Board.⁴⁴⁵

The following content areas have been identified as relevant for various aspects of PMTCT counselling; these should be

appropriately integrated into training that is specific to the different types of counselling (VCT, ANC, postnatal, family planning) and include the right supportive dialogue:

- The importance and benefits of women disclosing their HIV status to their male partners/husbands and the skills for disclosure.^{446,447} Counselling sessions are successful in helping women disclose their HIV status to their male partner/husband and in encouraging him to test.⁴⁴⁸ The research finding that there are often far fewer adverse consequences than expected when a woman discloses her HIV status to her male partner/husband should be communicated to counsellors.⁴⁴⁹
- In regard to gender-based violence, research has found that a range of men's violent behaviours, including sexual violence, increases women's risk of HIV infection and has a number of other impacts on a woman's health. Counsellors and other healthcare providers should receive training on how to deal with such issues.⁴⁵⁰
- Skills for couple counselling.⁴⁵¹
- VCT, which is considered an essential element of PMTCT services⁴⁵² and the entry point to PMTCT services.
- Women's rights,⁴⁵³ and more specifically, reproductive and sexual rights. Research has found that healthcare workers often react negatively to women who become pregnant.^{454,455}
- Up-to-date, consistent and accurate information on infant feeding.^{456,457,458}
- Family planning that emphasises the importance of dual protection to prevent pregnancies and (re)infection^{459,460} and appropriate advice and information for those who

440 McKee et al., 2004
441 McKee et al., 2004
442 UNICEF, 2002
443 McKee et al., 2004
444 McKee et al., 2004
445 Doherty et al., 2003

446 WHO & UNICEF, 2007
447 Msuya et al., 2008
448 Mahendra et al., 2007
449 Visser et al., 2008
450 Sonke Gender Justice Programme, 2008
451 Msuya et al., 2008
452 Moore, 2003
453 Scorgie & Crankshaw, 2008
454 McCarraher et al., 2008
455 London et al., 2008
456 Doherty et al., 2003
457 Coovadia & Bland, 2007
458 De Paoli et al., 2008
459 Mahendra et al., 2007
460 USAID, 2005

desire pregnancy.⁴⁶¹ Family-planning counsellors should be trained to support HIV-positive women in achieving their preferred sexual and reproductive health goals rather than imposing a particular position.⁴⁶²

- The impact of stigma and discrimination on the success of PMTCT programmes.
- Sensitisation workshops that encourage counsellors to explore their own attitudes and judgments towards their clients are important for reducing stigma and discrimination during subsequent counselling and consultations.⁴⁶³

461 Sable, Libbus, Jackson & Hausler, 2008

462 Baek & Rutenberg, 2005

463 Moore, 2003



12. Implications and recommended areas for future research

The literature appears focused on particular aspects of PMTCT. A large portion focuses on the issue of counselling and testing. This is an important area of research and deliberation, as research across South Africa in 2005 indicated that those who knew their HIV status (positive or negative) were more likely to use a condom with their partner than those who did not know their status. In addition, those who knew their HIV-positive status tended to use condoms more than those who knew they were HIV-negative.⁴⁶⁴ This highlights that counselling and testing is an important primary HIV-prevention intervention; thus, there is a need for continued efforts to encourage counselling and testing.

A considerable body of literature focuses on identifying and describing the barriers inhibiting the success of PMTCT programmes. These barriers exist at the individual level (e.g., a lack of knowledge), the community level (e.g., cultural practices and beliefs) and the structural level (e.g., a lack of adequate healthcare infrastructure). The range of barriers discussed in the literature reveals the importance of a communication response that ensures a balance between communication focused on the individual level and communication and efforts focused at bringing about social transformation — that is, community-oriented behaviour change.⁴⁶⁵

A large amount of scientific research has been conducted about infant feeding and MTCT. The research reported on in this review shows that infant feeding is a contentious and confusing issue, which has a significant impact at the grassroots level. Exclusive breastfeeding is currently receiving considerable attention as new findings emerge in support of this option as a feasible and sustainable infant-feeding practice in resource-poor contexts. However, there is a risk that the needs of women who choose to formula feed, or those who have to formula feed for a medical reason, are being overlooked in the research arena.

Another area that is receiving considerable interest is that of family planning, with a particular focus on the reproductive rights of HIV-positive women. Much of the research reviewed suggests that the family-planning needs of many HIV-positive and HIV-negative individuals go unmet, and that HIV-positive women often risk being discriminated

against if they choose to have a child.

The family-centred approach to health services was a reoccurring theme in the literature, but this, alongside the reproductive needs of youths, couples counselling, and testing and disclosure, has not received adequate attention.

12.1 Recommendations for future research

The review of the literature as a whole reveals the following areas are recommended for future research:

12.1.1 Gender

- The attitudes and beliefs of men and women about male involvement in family planning and PMTCT.
- Males' attitudes and behaviours that either prevent or promote safe motherhood.
- Males' attitudes towards counselling and testing.
- The impact of gender-based violence on PMTCT.

12.1.2 Individual experience and perception

- The various psychological barriers to PMTCT.
- Ways of increasing perceptions of risks.
- The experiences of HIV-positive women who have disclosed to their partners.
- The views and experiences of those accessing various PMTCT services.
- The levels of HIV/AIDS-related stigma and discrimination.

12.1.3 Knowledge

- HIV/AIDS and PMTCT knowledge among HIV-positive and HIV-negative men and women, male and female youths and healthcare workers. Why is HIV/AIDS knowledge in the South African population decreasing?⁴⁶⁶

464 Shisana et al., 2005

465 Moore, 2003

466 Shisana et al., 2009

12.1.4 Reproduction rights, desires, beliefs

- The attitudes of HIV-positive and HIV-negative men and women and healthcare workers towards HIV-positive mothers who choose to have children.
- The fertility desires and contraceptive practices of HIV-positive and HIV-negative men and women.
- The family-planning and PMTCT needs of young men and women of childbearing age.
- Cultural and gendered beliefs and attitudes towards disclosing HIV status and pregnancy.
- Cultural and gendered beliefs and practices around childbearing and childrearing.

12.1.5 Infant feeding

- The respective experiences of mothers who choose to breastfeed or to formula feed, particularly the coping strategies of women who manage to adhere to one particular approach exclusively.
- Attitudes to infant feeding, and the beliefs, influences and mechanisms through which young females learn about infant feeding.
- Infant-feeding practices.
- The various infant-feeding options, including current scientific findings.

12.1.6 Health systems

- How to make family-planning services more user-friendly.
- The mechanisms through which policy is communicated to relevant programme managers and healthcare workers and between government departments.
- The mechanisms through which referrals are made between different service providers.
- The level of integration of PMTCT services with other relevant services, including newborn/child health, treatment, family planning, ANC, and counselling and testing.

- The extent to which the family-centred model to health is being implemented and the possibility of scaling-up this model.
- The problems and successes of current PMTCT programmes.
- The possibility of more formally integrating lay counsellors, community health workers and PLWHA into PMTCT programmes.
- The feasibility and possibility of partnering with various NGOs, FBOs, and CBOs to improve the availability and uptake of various PMTCT services and to alleviate some of the workload stress of healthcare workers.

12.1.7 Counselling and testing

- The existence of couple-friendly counselling and the feasibility of introducing this into PMTCT programmes.
- The quality of VCT and the reasons why people in general do not agree to be tested.
- The current status of counselling training and curriculum development.

12.1.8 Communication

- Ways in which mass media can be used to communicate important PMTCT information and generate increased support from males.
- Ways in which community communication strategies can be improved to ensure that important information reaches a wide variety of people.
- The various sources from which people find out about MTCT and PMTCT services.



13. Conclusions

The review of the literature pertaining to barriers to PMTCT implementation suggests that an effective PMTCT communication strategy needs to consider three critical elements characterising HIV/AIDS and PMTCT in an African context:

1. Several very specific behaviours at the individual level are needed for PMTCT.
2. A number of cultural and relational dynamics impact on the effectiveness of PMTCT programmes.
3. PMTCT programmes are weakened by wider contextual factors, which include social norms, policy-related decisions, and the quality of the healthcare system.

In such a context, the use of communication strategies driven solely by theories of behaviour is neither appropriate nor ethical. The literature confirms that what is needed is an integrated communication strategy that recognises the social complexity of HIV/AIDS and PMTCT.⁴⁶⁷

The available literature about PMTCT in largely under-resourced contexts indicates that the most appropriate strategy for effective PMTCT communication is one based on the model and assumptions of communication for social change. This is an integrated model of communication that promotes collective discussion and debate and individual reflection and behaviour change, while also recognising the importance of addressing the complex set of social, cultural, economic and political factors that serve to undermine PMTCT interventions.^{468,469}

The review of the literature confirms that a number of barriers currently prevent the successful implementation of PMTCT programmes, having critical implications for the design of effective PMTCT communication strategies. The literature review as a whole allows us to recognise that:

- A number of key participants need to be included in the design and implementation of PMTCT communication strategies. Emphasis should be placed on developing an integrated social network of relevant participants who, through participatory activities and dialogue, can engage in the process of developing an appropriate, integrated and synergistic communication strategy.

- Pregnant women and mothers should not be the sole focus of PMTCT campaigns. It is clear from the available research that unless there is a social network of support, PMTCT programmes are not likely to be effective. Communication must focus on a range of participants to enable supportive, integrated and pro-active responses to the challenges facing PMTCT implementation.
- Communication programmes should be directed at all age groups and both genders, and included in both rural and urban spaces. There is currently an emphasis on reaching pregnant women and messages in urban spaces.
- Communication will only be effective in bringing about appropriate behaviour change at the individual level if it occurs within, and supports the development of, a supportive and health-enabling environment. There is a need to work within a human-rights framework (with particular emphasis on the reproductive and sexual rights of women) in order to strengthen the healthcare system, integrate services within the healthcare system, and address the impacts of stigma, discrimination and gender inequity if mothers are expected to enrol in, and stay enrolled in, PMTCT programmes. This implies the importance of communication with, and between, relevant government departments and community-based organisations.
- Communication campaigns should invest in strengthening interpersonal, community, and mass media communication strategies in a way that ensures integrated and consistent PMTCT messages.
- Communication strategies should be based on the findings of up-to-date participatory research.

The recently released 'Department of Health — Strategic Plan (2009/10–2011/12)'⁴⁷⁰ supports the overall findings of this review, and it is likely to bolster the effectiveness of PMTCT communication campaigns. The plan demonstrates support for the revival of constructive grassroots participation in health service delivery. The DoH's 'Policy and Guidelines for the Implementation of the PMTCT Programme, 2008' also lends support to designing and implementing effective communication strategies and further confirms the

467 Vincent, 2006

468 Vincent, 2006

469 Scalway, 2002

470 Department of Health [South Africa], 2009a

findings of this review; especially, the document recognises the roles of leadership and partnership and the importance of creating supportive social environments to strengthen the national PMTCT programme.



References

- Adeneye, A.K., Mafe, M.A., Adeneye, A.A., Salami, K.K., Brieger, W.R., Titiloye, M.A., Adewole, T.A. & Agomo, P.U. (2006) Knowledge and perception of HIV/AIDS among pregnant women attending antenatal clinics in Ogun State, Nigeria. *African Journal of AIDS Research* 5(3), 275–279.
- Airhihenbuwa, C.O., Makinwa, B. & Obregon, R. (2000) Toward a new communications framework for HIV/AIDS. *Journal of Health Communications* 5(supplement), 101–111.
- Almroth, S., Arts, M., Quang, D.N., Hoa, P.T.T. & Williams, C. (2008) Exclusive breastfeeding in Vietnam: An attainable goal. *Acta Paediatrica* 97, 1066–1069.
- Baek, C., Creek, T., Jones, L., Apicella, L., Redner, J. & Rutenberg, N. (2009) *Evaluation of HIV counselling and testing in ANC settings and adherence to short-course antiretroviral prophylaxis for PMTCT in Francistown, Botswana*. Washington, D.C.: Population Council.
- Baek, C. & Rutenberg, N. (2005) *Addressing the family planning needs of HIV-positive PMTCT clients: Baseline findings from an operations research study*. Horizons Research Update. Washington, D.C.: Population Council.
- Baiden, F., Remes, P., Baiden, R., Williams, J., Hodgson, A., Boelaert, M. & Buve, A. (2005) Voluntary counselling and HIV testing for pregnant women in the Kassena-Nankana district of northern Ghana: Is couple counselling the way forward? *AIDS Care* 17(5), 648–657.
- Barker, K. & Sabido, M. (2005) *Soap operas for social change to prevent HIV/AIDS: A training guide for journalists and media personnel*. Vermont: Population Media Center.
- Bateman, C. (2008) Izindaba. Finally — PMTCT dual therapy. *South African Medical Journal* 3(98), 174.
- Booth, P. (2008) *Making progress against AIDS? The state of South Africa's response to the HIV/AIDS and TB epidemics*. Cape Town: South African National AIDS Council (SANAC).
- Booth, P. (2009) E-mail up-date communication from SANAC Deputy Chair. Cape Town: South African National AIDS Council (SANAC).
- Boulay, M., Storey, J.D. & Sood, S. (2002) Indirect exposure to a family-planning mass media campaign in Nepal. *Journal of Health Communication* 7, 379–399.
- Bradshaw, D., Chopra, M., Kerber, K., Lawn, J., Moodley, R., Pattison, R., Patrick, M., Stephen, C. & Velaphi, S. (2008) *Every death counts: Saving the lives of mothers, babies and children in South Africa*. Pretoria: Department of Health, Medical Research Council, University of Pretoria, Save the Children and UNICEF.
- Burke, J. (2004) Infant HIV infection: Acceptability of preventive strategies in Central Tanzania. *AIDS Education and Prevention* 16(5), 415–425.
- Chigwedere, P., Seage, G.R., Gruskin, S., Lee, T.H. & Essex, M. (2008) Estimating the lost benefits of ARV drugs in South Africa. *Journal of Acquired Immune Deficiency Syndromes* 49, 410–415.
- Chopra, M., Doherty, T., Jackson, D. & Ashworth, A. (2005) Preventing HIV transmission to children: Quality of counselling of mothers in South Africa. *Acta Paediatrica* 94, 357–363.
- Chopra, M., Piwoz, E., Songwana, J., Schaay, N., Dunnett, L. & Saders, D. (2002) Effect of a mother-to-child-HIV-prevention programme on infant feeding and caring practices in South Africa. *South African Medical Journal* 92(4), 298–302.
- Chopra, M. & Rollins, N. (2008) Infant feeding in the time of HIV: Rapid assessment of infant feeding policy and programmes in four African countries scaling-up prevention-of-mother-to-child-transmission programmes. *Archives of Disease in Childhood* 93, 288–291.
- Clark, P.A. (2006) Mother-to-child transmission in Botswana: An ethical perspective on mandatory testing. *Developing World Bioethics* 6(1), 1–12.
- Connor, E., Sperling, R.S., Gelber, R., Kiselev, P., Scott, G., O'Sullivan, M.J., VanDyke, R., Bey, M., Shearer, W., Jacobson, R.L., Jimenez, E., O'Neill, E., Bazin, B., Delfraissy, J., Culnane, M., Coombs, R., Elkins, M., Moya, J., Stratton, P. & Balseley, J. for The Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. (1994) Reduction of Maternal-Infant

- Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment. *The New England Journal of Medicine* 331(18), 1173–1180.
- Cooper, D. (2008) In pursuit of social development goals and HIV-infected women's reproductive rights: South Africa as a case study. *Agenda* 75, 4–15.
- Coovadia, A. (2009) Courting mortality: The fight to PMTC HIV transmission. In: Cullinan, K. & Thom, A. (eds.) *The virus, vitamins and vegetables: The South African HIV/AIDS mystery* (pp. 58–76). Johannesburg: Jacana.
- Coovadia, H.M. & Bland, R.M. (2007) Preserving breastfeeding practices through the HIV pandemic. *Tropical Medicine and International Health* 12(9), 1116–1133.
- Coutsoudis, A., Coovadia, H.M. & Wilfret, C.M. (2008) HIV, infant feeding and more perils for poor people: New WHO guidelines encourage review of formula milk policies. *Bulletin of the World Health Organization* 86(3), 210–214.
- Creek, T., Ntuny, R., Seipone, K., Smith, M., Mogodi, M., Smit, M., Legwaila, K., Molokwane, I., Tebele, G., Mazhani, L., Shaffer, N. & Kilmarx, P.H. (2007) Successful introduction of routine opt-out HIV testing in antenatal care in Botswana. *Journal of Acquired Immune Deficiency Syndromes* 45(1), 102–107.
- Dahl, V., Mellhammar, L., Bajunirwe, F. & Bjorkman, P. (2008) Acceptance of HIV testing among women attending antenatal care in south-western Uganda: Risk factors and reasons for test refusal. *AIDS Care* 20(6), 746–752.
- Delvaux, T., Diby Konan, J.P., Ake-Tano, O., Gohou-Kouassi, V., Emery Basso, P., Buvé, A. & Ronsmans, C. (2008) Quality of antenatal and delivery care before and after the implementation of a prevention-of-mother-to-child-HIV-transmission programme in Cote d'Ivoire. *Tropical Medicine and International Health* 13(8), 970–979.
- De Paoli, M.M., Mkhwanazi, N.B., Richter, L.M. & Rollins, N. (2008) Early cessation of breastfeeding to prevent postnatal transmission of HIV: A recommendation in need of guidance. *Acta Paediatrica* 97, 1663–1668.
- Department of Health [South Africa] (2007) *HIV and AIDS and STIs strategic plan for South Africa, 2007–2011*. Pretoria: National Department of Health.
- Department of Health [South Africa] (2008a) *The national HIV and syphilis prevalence survey, South Africa*. Pretoria: National Department of Health.
- Department of Health [South Africa] (2008b) *Policy and guidelines for the implementation of the PMTCT programme*. Pretoria: National Department of Health.
- Department of Health [South Africa] (2009a) *Department of Health strategic plan 2009/10–2011/12*. Pretoria: National Department of Health.
- Department of Health [South Africa] (2009b) Budget speech by Dr Aaron Motsoaledi. Available at: <http://www.doh.gov.za/docs/sp/2009/sp0630.html> [Accessed 17 July 2009].
- Department of Health [South Africa] (2009c) Press conference with Dr Aaron Motsoaledi. Available at: <http://www.doh.gov.za/docs/sp/sp0518-f.html> [Accessed 17 July 2009].
- Doherty, T., Besser, M., Donohue, S., Kamoga, N., Stoops, N., Williamson, I. & Visser, R. (2003) *An evaluation of the PMTCT of HIV initiative in South Africa: Lessons and recommendations*. A report for the National Department of Health. Durban: Health Systems Trust.
- Doherty, T., Chopra, M., Nkoki, L., Jackson, D. & Greiner T. (2006) Effect of the HIV epidemic on infant feeding in South Africa: 'When they see me coming with the tins they laugh at me.' *Bulletin of the World Health Organization* 84(2), 90–96.
- Doherty, T., McCoy, D. & Donohue, S. (2005) Health system constraints to optimal coverage of the prevention-of-mother-to-child-HIV-transmission programme in South Africa: Lessons from the implementation of the national pilot programme. *African Health Sciences* 5(3), 213–218.
- Eide, M., Myhre, M., Lindbaek, M., Sundby, J., Arimi, P. & Thior, I. (2006) Social consequences of HIV-positive women's participation in PMTCT programmes. *Patient Education and Counselling* 60, 146–151.



- Eyakuze, C., Jones, D.A., Starrs, A.M. & Sorkin, N. (2008) From PMTCT to a more comprehensive AIDS response for women: A much-needed shift. *Developing World Bioethics* 8(1), 33–42.
- Farlane, L. (2008) HIV-positive women have family planning needs too. *Agenda* 75, 31–37.
- Figueroa, M.E., Kincaid, D.L., Rani, M. & Lewis, G. (2002) *Communication for social change: An integrated model for measuring the process and its outcomes*. New York: Rockefeller Foundation.
- Garson, P. (2005) 'Men think we bring the disease': Challenges facing HIV-positive mothers in Soweto. *Baby steps: Reporting on PMTCT*. An HIV/AIDS indaba hosted by the Nelson Mandela Foundation, in partnership with the Perinatal HIV Research Unit and the Media Project. Johannesburg: Nelson Mandela Foundation.
- Gupta, D., Lhewa, D., Vishwanath, R., Jacob, S.M., Parameshwari, S., Radhakrishnan, R., Seidel, K., Frenkel, L.M., Samuel, N.M. & Melvin, A.J. (2007) Effectiveness of antenatal group HIV voluntary counselling and testing services in rural India. *AIDS Education and Prevention* 19(3), 187–197.
- Haider, R., Kabir, I. & Huttly, S.R.A. (2000) Effects of community-based peer counsellors on exclusive breastfeeding. *The Lancet* 356, 1643–1647.
- Horizons (2009) *Family-centered approach for HIV services: Pilot study in South Africa*. Washington, D.C.: Population Council.
- IMAU & CDC [Uganda] (2003) Report on the Formative Study on Community Mobilization Intervention Model for PMTCT/ART. Kampala, Uganda: The Islamic Medical Association of Uganda (IMAU) with Centers for Disease Control and Prevention (CDC, Uganda).
- International HIV/AIDS Alliance (2009) *Linkages and integration of sexual and reproductive health, rights and HIV: Good practice update, March 2009*. Hove, United Kingdom: International HIV/AIDS Alliance.
- Jones, S.A., Sherman, G.G. & Varga, C. (2005) Exploring socio-economic conditions and poor follow-up rates of HIV-exposed infants in Johannesburg, South Africa. *AIDS Care* 17(4), 466–470.
- Kagee, A. (2008) Adherence to ARV therapy in the context of the national roll-out in South Africa: Defining a research agenda for psychology. *South African Journal of Psychology* 38(2), 413–428.
- Kasenga, F., Byass, P., Emmelin, M. & Hurtig, A. (2009) *The implications of policy changes on the uptake of a PMTCT programme in rural Malawi: First three years of experience*. Atlanta, Georgia: Global Health Action.
- Keabaetswe, P.M. (2007) Barriers to participation in the prevention-of-mother-to-child-transmission program in Gaborone, Botswana: A qualitative approach. *AIDS Care* 19(3), 355–360.
- Kgwete, M. (2008) Beyond denial: Women's dilemmas and choices around HIV testing, treatment and disclosure. *Agenda* 75, 4–15.
- Khan, H. (2007a) *Horizons Report: Operations research in HIV/AIDS*. Washington, D.C.: Population Council.
- Khan, H. (2007b) *From mother to mother: A peer mentor program to prevent mother-to-child transmission of HIV in South Africa offers much-needed support*. Washington, D.C.: Population Council.
- Kim, C.R. & Free, C. (2008) Recent evaluations of the peer-led approach in adolescent sexual health education: A systematic review. *International Family Planning Perspectives*, 34(2), 89–96.
- Kincaid, D.L. & Parker, W. (2008) *National AIDS communication programmes, HIV prevention behaviour, and HIV infections averted in South Africa, 2005*. Pretoria: Johns Hopkins Health and Education in South Africa (JHHESA).
- Kincaid, D.L., Parker, W., Schierhout, G., Connolly, C. & Pham, V.H.T. (2008) *AIDS communication programme, HIV prevention, and living with HIV and AIDS in South Africa, 2006: A summary*. Pretoria: Johns Hopkins Health and Education in South Africa (JHHESA).
- King, R., Katuntu, D., Lifshay, J., Packel, L., Batamwita, R., Nakayiwa, S., Abang, B., Babirye, F., Lindkvist, P., Johansson, E., Mermin, J. & Bunnell, R. (2008) Process and outcomes of HIV-serostatus disclosure to sexual partners among people living with HIV in Uganda. *AIDS Behaviour* 12, 223–243.

- Kizito, D., Woodburn, P.W., Kesande, B., Ameke, C., Nabulime, J., Muwanga, M., Grosskurth, H. & Elliott, M. (2008) Uptake of HIV and syphilis testing of pregnant women and their male partners in a programme for prevention of mother-to-child HIV transmission in Uganda. *Tropical Medicine and International Health* 13(5), 680–682.
- Langen, T.T. (2005) Gender power imbalance on women's capacity to negotiate self-protection against HIV/AIDS in Botswana and South Africa. *African Health Sciences* 5(3), 188–197.
- London, L., Orner, P.J. & Myer, L. (2008) 'Even if you're positive, you still have rights because you are a person': Human rights and the reproductive choice of HIV-positive persons. *Developing World Bioethics* 8(1), 11–22.
- Mahendra, V.S., Mudoji, R., Oinam, A., Pakkela, V. & Sarna, A. (2007) *Continuum of care for HIV-positive women accessing programs to prevent parent-to-child transmission: Findings from India*. Washington, D.C.: Population Council.
- Manzi, M., Zachariah, R., Teck, R., Buhendwa, L., Kazima, J., Bakali, E., Firmenich, P. & Humblet, P. (2005) High acceptability of voluntary counselling and HIV testing, but unacceptable loss to follow-up in a PMTCT-HIV-transmission programme in rural Malawi: Scaling-up requires a different way of acting. *Tropical Medicine and International Health* 10(12), 1242–1250.
- Mate, K.S., Bennett, B., Mphatswe, W., Barker, P. & Rollins, N. (2009) Challenges for routine health-system data management in a large public programme to prevent mother-to-child HIV transmission in South Africa. *PLoS One* 4(5), e5483 [online].
- Matji, J.N., Wittenberg, D.F., Makin, J.D., Jeffery, B., MacIntyre, U.E. & Forsyth, B.W.C. (2008) Psychosocial and economic determinants of infant-feeding intent by pregnant women in Tshwane/Pretoria. *South African Journal of Child Health* 2(3), 114–118.
- McCarragher, D., Cuthbertson, C., Kung'u, D., Otterness, C., Johnson, L. & Magiri, G. (2008) Sexual behaviour, fertility desires and unmet need for family planning among home-based care clients and caregivers in Kenya. *AIDS Care* 20(9), 1057–1065.
- McKee, N., Bertrand, J.T. & Becker-Benton, A. (2004) *Strategic communication in the HIV/AIDS epidemic*. California: Sage Publications.
- Medley, A., Garcia-Moreno, C., Gill, S.M. & Maman, S. (2004) Rates, barriers and outcomes of HIV-serostatus disclosure among women in developing countries: Implications for PMTCT programmes. *Bulletin of the World Health Organization* 82(4), 299–307.
- Meintjies, H. & Bray, R. (2005) 'But where are our mortal heroes?' An analysis of South African press reporting on children affected by HIV/AIDS. *African Journal of AIDS Research* 4(3), 147–159.
- Melkote, S.R., Muppide, S.R. & Goswami, D. (2000) Social and economic factors in an integrated behavioural and societal approach to communication in HIV/AIDS. *Journal of Health Communication* 5, 17–27.
- Mlay, R., Lungina, H. & Becker, S. (2008) Couple counselling and testing for HIV at antenatal clinics: Views from men, women and counsellors. *AIDS Care* 20(3), 356–360.
- Moore, M. (2003) *A behaviour-change perspective on integrating PMTCT and safe motherhood programs*. Washington, D.C.: Academy for Educational Development (AED).
- Mothers2Mothers (m2m) (2007) *Annual Report*. Cape Town: Mothers2Mothers.
- Msuya, S.E., Mbizvo, E.M., Hussain, A., Uriyo, J., Sam, N.E. & Stray-Petersen, B. (2008) Low male partner participation in antenatal HIV counselling and testing in northern Tanzania: Implications for preventive programs. *AIDS Care* 20(6), 700–709.
- Mullick, S., Kunene, B. & Wanjiru, M. (2005) Involving men in maternity care: Health service delivery issues. *Agenda Special Focus* 2005, 126.
- Mushi, D.L., Mpembeni, R.M. & Jahn, A. (2007) Knowledge about safe motherhood and HIV/AIDS among school pupils in a rural area in Tanzania. *BMC Pregnancy and Childbirth* 7(1), 5.



- Myhre, S.L. & Flora, J.A. (2000) HIV/AIDS communication campaigns: Progress and prospects. *Journal of Health Communication* 5, 29–45.
- Nair, Y. & Campbell, C. (2008) Building partnerships to support community-led HIV/AIDS management: A case study from rural South Africa. *African Journal of AIDS Research* 7(1), 45–53.
- Nakayiwa, S., Abang, B., Packel, L., Lifshay, J., Purcell, D.W., King, R., Ezati, E., Mermin, J., Coutinho, A. & Bunnell, R. (2006) Desire for children and pregnancy-risk behaviour among HIV-infected men and women in Uganda. *AIDS and Behaviour* 10(supplement), S96–S104.
- Noar, S.M., Palmgreen, P., Chabot, M., Dobransky, N. & Zimmerman, R.S. (2009) A 10-year systematic review of HIV/AIDS mass communication campaigns: Have we made progress? *Journal of Health Communication* 14, 15–52.
- Nuwagaba-Biribonwoha, H., Mayon-White, R.T., Okong, P. & Carpenter, L.M. (2007) Challenges faced by health workers in implementing the prevention-of-mother-to-child-HIV-transmission (PMTCT) programme in Uganda. *Journal of Public Health* 29(3), 269–274.
- Ogudele, M.O. & Coulter, J.B.S. (2003) HIV transmission through breastfeeding: Problems and prevention. *Annals of Tropical Pediatrics* 23, 91–106.
- Okonkwo, K.C., Reich, K., Alabi, A.I., Umeike, N. & Nachman, S.A. (2007) An evaluation of awareness: Attitudes and beliefs of pregnant Nigerian women toward voluntary counselling and testing for HIV. *AIDS Patient Care and STDs* 21(4), 252–260.
- Orne-Glieman, J., Mukotekwa, T., Perez, F., Miller, A., Sakarovitch, C., Glenshaw, M. & Engelsmann (2006) Improved knowledge and practices among end-users of MTCT of HIV-prevention services in rural Zimbabwe. *Tropical Medicine and International Health* 11(3), 341–349.
- PAHO/WHO, UNICEF, CENSIDA & Mexico (2002) Regional consultation on the use of communication for PMTCT, 6–8 February 2002. Cuernavaca, Mexico: PAHO/WHO, UNICEF and CENSIDA.
- Painter, T.M., Diaby, K.L., Matia, D.M., Lin, L.S., Sibailly, T.S., Kouassi, M.K., Ekpini, E.R., Roels, T.H. & Wiktor, S.Z. (2004) Women's reasons for not participating in follow-up visits before starting short-course antiretroviral prophylaxis for prevention of mother-to-child transmission of HIV: Qualitative interview study. *British Medical Journal* 329, 5.
- Peacock, D., Redpath, J., Weston, M., Evans, K., Daub, A. & Greig, A. (2008) *Literature review on men, gender, health and HIV and AIDS in South Africa*. Johannesburg: Sonke Gender Justice Network.
- Peltzer, K., Mosala, T., Shisana, O., Nqeketo, A. & Mngqundaniso, N. (2007) Barriers to prevention of HIV transmission from mother to child (PMTCT) in a resource-poor setting in the Eastern Cape, South Africa. *African Journal of Reproductive Health* 11(1), 57–66.
- PEPFAR (2004) *Annual report on PMTCT of HIV infection*. Washington, D.C.: The U.S. President's Plan for AIDS Relief (PEPFAR).
- Perez, F., Mukotekwa, T., Miller, A., Orne-Gliemann, J., Glenshaw, M., Chitsike, I. & Dabis, F. (2004) Implementing a rural programme of PMTCT of HIV in Zimbabwe: First 18 months of experience. *Tropical Medicine and International Health* 9(7), 774–783.
- Petrie, K.E., Schmidt, S.D., Schwarz, C.E., Koornhof, H.E. & Marias, D. (2007) Knowledge, attitudes and practices of women regarding the prevention of mother-to-child transmission (PMTCT) programme at the Vanguard Community Health Centre, Western Cape — A pilot study. *South African Journal Clinical Nutrition* 20(2), 71–78.
- Pillsbury, B. & Mayer, D. (2005) Women connect! Strengthening communications to meet sexual and reproductive health challenges. *Journal of Health Communication* 10, 361–371.
- Program for Appropriate Technology in Health (PATH) (2006) *Magnet theatre: Involving audiences and encouraging change*. Nairobi, Kenya: PATH.

- Promundo Salud y Genero, ECOS, Instituto PAPAÍ & World Education (no date) *Working with young women: Empowerment, rights and health*. New York: Promundo.
- Reynolds, H.W., Janowitz, B., Wilcher, R. & Cates, W. (2008) Contraception to prevent HIV-positive births: Current contributions and potential cost savings in PEPFAR countries. *Sexually Transmitted Infections* 84(supplement 2), 49–53.
- Ricardo, C., Barker, G., Nascimento, M. & Segundo, M. (2008) *Young men and HIV prevention: A toolkit for action*. New York: Promundo and UNFPA.
- Rigard, N. (2005) 'If you want to see me bright, touch on the questions': Attitudes of health care workers to the PMTCT in a rural area: An HIV/AIDS indaba hosted at the Nelson Mandela Foundation, in partnership with the Perinatal HIV Research Unit and The Media Project.
- Rutenberg, N. & Baek, C. (2004) *Review of field experiences: Integration of family planning and PMTCT services*. New York: Population Council.
- Sable, M.R., Libbus, M.K., Jackson, D. & Hausler, H. (2008) The role of pregnancy intention in HIV prevention in South Africa: A proposed model for policy and practice. *African Journal of AIDS Research* 7(2), 159–165.
- Sarker, M., Sanou, A., Snow, A., Ganame, J. & Gondo, A. (2007) Determinants of HIV counselling and testing participation in a PMTCT programme in rural Burkino Faso. *Tropical Medicine and International Health* 12(12), 1475–1483.
- Save the Children (2009) *State of the world's mothers: Investing in the early years*. Connecticut: Save the Children.
- Scalway, T. (2001) *Young men and HIV: Culture, poverty and sexual risk*. London: Panos and UNAIDS.
- Scalway, T. (2002) *Critical challenges to HIV communication*. London: Panos.
- Scorgie, F. & Crankshaw, T. (2008) Band-aid for a gaping wound: Can mandatory HIV-testing of newborns improve the success of PMTCT? *Agenda* 75, 54–60.
- Seidel, G. (2000) Reconceptualising issues around HIV and breastfeeding advice: Findings from KwaZulu-Natal South Africa. *Review of African Political Economy* 27(86), 501–518.
- Shankar, A.V., Pisal, H., Patil, O., Joshi, A., Suryavananshi, N., Shrotri, A., Bharucha, K.E., Bulakh, P., Phadke, M.A., Bollinger, R.C. & Sastry, J. (2003) Women's acceptability and husbands' support of rapid testing of pregnant women in India. *AIDS Care* 15(6), 871–874.
- Shetty, A.K., Marangwanda, C., Stranix-Chibanda, L., Chandisarewa, W., Chirapa, E., Mahomva, A., Miller, A., Simoyi, M. & Maldonado, Y. (2008) The feasibility of preventing mother-to-child transmission of HIV using peer counsellors in Zimbabwe. *AIDS Research and Therapy* 5(17), 1–8.
- Shisana, O., Rehele, T., Simbayi, L.C., Zuma, W., Connolly, C., Jooste, S. & Pillay, V. (eds) (2005) *1st South African national HIV prevalence, HIV incidence, behaviour and communication survey*. Cape Town: HSRC Press.
- Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Pillay-Van Wyk, V., Mbelle, N., Van Zyl, J., Parker, W., Zungu, N.P., Pezi, S. & The SABSSM III Implementation Team (2009) *South African national HIV prevalence, incidence, behaviour and communication survey 2008: A turning tide among teenagers?* Cape Town: HSRC Press.
- Shisana, O. & Simbayi, L. (2002) *Nelson Mandela HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media*. Cape Town: HSRC Press.
- Skinner, S., Mfecane, S., Gumede, T., Henda, N. & Davids, A. (2005) Barriers to accessing PMTCT services in a rural area of South Africa. *African Journal of AIDS Research* 4(2), 115–123.
- Skinner, D., Mfecane, S., Henda, N., Dorkenoo, E., Davids, A. & Shisana, O. (2003) *Situational analysis of PMTCT services in regions of the Eastern Cape*. Cape Town, HSRC Press.
- Sonke Gender Justice Project (2008) *Men for change, health for all: A policy discussion on men, health and gender equity*. Johannesburg: Sonke Gender Justice Project.
- South African National AIDS Council (SANAC) Policy Implementation Committee (PIC) (2009) Draft minutes of the SANAC Programme Implementation Committee meeting, July 2009.



- Spensley, A., Sripipatana, T., Turner, A.N., Hoblitzelle, C., Robinson, J. & Wilfert, C. (1999) Preventing mother-to-child transmission of HIV in resource-limited settings: The Elizabeth Glaser Paediatric AIDS Foundation experience. *Research and Practice* 4, 631–637.
- Spurr, N. (2005) *Who is setting the PMTCT agenda? A quantitative content analysis of media coverage of PMTCT in South Africa*: An HIV/AIDS indaba hosted at the Nelson Mandela Foundation, in partnership with the Perinatal HIV Research Unit and The Media Project.
- Stackpool-Moore, L. (2006) *'We are one but we are many': New thinking on how communication can support HIV social movements to achieve inclusive social change*. London: Panos AIDS Programme.
- Stevens, M. (2008) Towards treatment guidelines for women of reproductive age: recognising the right to choose. *Agenda* 75, 67–77.
- Tadesse, E., Muula, A.S. & Misiri, H. (2004) Likely stakeholders in the prevention of mother-to-child transmission of HIV/AIDS in Blantyre, Malawi. *African Health Sciences* 4(3), 155–159.
- Tavengwa, N.V., Piwoz, E.G., Iliff, P.J., Moulton, L.H., Zunguza, C.D., Nathoo, K.J., Hargrove, J.W., the ZVITAMBO Study Group & Humphrey, J.H. (2007) Adoption of safer infant feeding and postpartum sexual practices and their relationship to maternal HIV status and risk of acquiring HIV in Zimbabwe. *Tropical Medicine and International Health* 12(1), 97–106.
- Tearfund (2008) *Scaling-up prevention of MTCT of HIV: Summary document*. July 2008. Teddington, United Kingdom: Tearfund.
- Thairu, L.N., Pelto, G.H., Rollins, N.C., Bland, R.M. & Ntshangase, N. (2005) Sociocultural influences on infant feeding decisions among HIV-infected women in rural KwaZulu-Natal, South Africa. *Maternal and Child Nutrition* 1(1), 2–10.
- The Communication Initiative Network (2003) *Continuing PMTCT communication in South Africa*. Victoria, British Columbia, Canada: The Communication Initiative.
- Thorsen, V.C., Sundby, J. & Martinson, F. (2008) Potential initiators of HIV-related stigmatisation: Ethical and programmatic challenges for PMTCT programs. *Agenda* 75, 4–15.
- Tlebere, P., Jackson, D., Loveday, M., Matizirofa, L., Mbombo, N., Doherty, T., Wigton, A., Treger, L. & Chopra, M. (2007) Community-based situation analysis of maternal and neonatal care in South Africa to explore factors that impact on the utilisation of maternal health services. *Journal of Midwifery and Women's Health* 52(4), 342–350.
- Tonwe-Gold, B., Ekouevi, D.K., Bosse, C.A., Toure, S., Koné, M., Becquet, R., Leroy, V., Toro, P., Dabis, F., El Sadr, W. M. & Abrams, E. J. (2009) Implementing family-focused HIV care and treatment: The first two years' experience of the mother-to-child-transmission-plus program in Abidjan, Cote d'Ivoire. *Tropical Medicine and International Health* 14(2), 204–212.
- Towle, M. & Lende, D. (2008) Community approaches to preventing mother-to-child HIV transmission: Perspectives from rural Lesotho. *African Journal of AIDS Research* 7(2), 219–228.
- UNAIDS & WHO (2008) *Fact sheet: Sub-Saharan Africa*. Geneva: UNAIDS.
- UNICEF (2000) *Generic communication strategy for PMTCT*. July 2000. East and Southern Africa: United Nations Children's Fund (UNICEF).
- UNICEF (2002) *Better practices in communication for prevention of HIV transmission in pregnant women, mothers and their children*. New York: United Nations Children's Fund (UNICEF).
- UNICEF (2009) *The state of the world's children: Maternal and newborn health*. December 2008. New York: United Nations Children's Fund (UNICEF).
- USAID (2005) *In Focus: Women and AIDS: Prevention of mother-to-child HIV transmission*. Washington, D.C.: USAID.
- USAID, FHI & DoH [South Africa] (2005) *Country Assessment: South Africa. Family Planning Needs in the Context of the HIV/AIDS Epidemic*. March 2005. USAID, Family Health International (FHI) and the Department of Health (DoH).

- USAID/Johns Hopkins University/JHU Programme in South Africa (2009) *Strategic plan 2008–2013*. January 2009. South Africa: JHU Programme in South Africa.
- Varga, C. & Brookes, H. (2008) Preventing mother-to-child transmission among South African adolescents. *Journal of Adolescent Research* 23(2), 172–205.
- Varga, C.A., Sherman, G.G. & Jones, S.A. (2006) HIV-disclosure in the context of vertical transmission: HIV-positive mothers in Johannesburg, South Africa. *AIDS Care* 18(8), 952–960.
- Vincent, R. (2006) *Breaking barriers: Effective communication for universal access to HIV prevention, treatment, care and support by 2010*. London: Panos.
- Visser, M.J., Neufeld, S., De Villiers, A., Makin, J.D. & Forsyth, B.W.C. (2008) To tell or not to tell: South African women's disclosure of HIV status during pregnancy. *AIDS Care* 20(9), 1138–1145.
- Waisbord, S. (2001) *Family tree of theories, methodologies and strategies in development communication*. New York: Rockefeller Foundation.
- WHO (2006) *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants in resource-limited settings — Towards universal access: Recommendations for a public health approach*. Geneva: World Health Organization (WHO).
- WHO (2007) *PMTCT briefing note: Department of HIV/AIDS*. Geneva: World Health Organization (WHO).
- WHO, UNAIDS & UNICEF (2008) *Towards universal access: Scaling-up priority HIV/AIDS interventions in the health sector. Progress report*. Geneva: World Health Organization (WHO).
- WHO & UNICEF (2007) *Guidance on global scale-up of the prevention of mother-to-child transmission of HIV: Towards universal access for women, infants and young children and eliminating HIV and AIDS among children*. Geneva: World Health Organization (WHO) and United Nations Children's Fund (UNICEF).
- Zambia Central Board of Health (2004) *Zambia national PMTCT communication strategy: Mobilising people for action*. Lusaka: Zambia Central Board of Health.